Involving older patients in their general practice care

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Involving older patients in their general practice care

een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

Proefschrift

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Contents

For reasons of consistency within this thesis, some terms have been standardised throughout the text. As a consequence the text may differ from the articles that have been published.

Introduction

1

This thesis is about the involvement of older patients in their general practice care. The concept of involvement is an outgrowth of concepts and ideas from the last four decades, therefore this introductory chapter starts with a historical perspective of views on consultations in general practice. In this thesis we consider involvement as enabling patients to take an active role in deciding about and planning their health care. As a part of involvement we consider peoples' self-management as patient behaviour, which keeps illness under control and minimises its impact on health and quality of life, it also includes deciding whether or not to seek health care. It is questionable whether involvement is suitable for all patients, therefore a general introduction of older patients and their possible involvement in general practice care is given, and key-questions are posed. Then, older patients with respect to their (co) morbidity are described, followed by an explanation of the concept of involvement, self-management and its aims. In more detail, attention will be paid to older patients' and general practitioners' (GPs) known attitudes and their behaviour in the issue of involvement. Next, some ideas of possible interventions to support involvement are described. Finally, the research questions and the content of thesis are described.

1.1 Historical perspective

Consultations are one of the cornerstones of general practice care. The consultation process and its outcome are strongly related and are important in the quality of general practice care. Of 1000 people in the population, 80% report symptoms, one third considers seeking medical care for these symptoms, 11% visit a primary care physician's office, and 2% are referred to a hospital outpatient clinic[1]. These observations have not changed appreciably compared to 1961[2]. In the Netherlands a study showed the same figures: one in five respondents consulted their GP and approximately 10% of the complaints were reported to the GP[3]; about one-third of all complaints led to medicine taking. A combination of good communication in consultations together with good technical care is needed for optimal patient care[4]. Next, some ideas and concepts of the last four decades are described, without the conviction of being complete.

As a background to how patients and doctors encounter, Michael Balint, a Hungarian psychiatrist and Cecil Helman, an anthropologist presented the following ideas. Balint (1957) suggested that doctors have an unique, but fixed way of interacting with patients; doctors also have, because of their personality, a therapeutic effect on patients; and patients adopt a sick role, which makes them dependent of, amongst others, the doctor[5]. Helman (1981) did some

suggestions about why a patient comes to a doctor and what questions exist in a patient's mind: What has happened? Why has it happened? Why to me? Why now? What would happen if nothing was done about it? What should I do about it and who should I consult for further help?[6].

During the years several models and concepts were developed for the doctor-patient relation and communication. In 1975 the Health Belief Model of Becker and Maiman showed the importance of the exploration of patients' health beliefs and the interpretation of these beliefs[7].

In 1976 Byrne and Long analysed more than 2000 consultations and identified six logical phases to a consultation (establishment of relationship, discovering reasons for attendance, examination, considering of condition, agreement on treatment of investigation and termination of contact). They also stressed that this logical structure rarely appears in reality to its full extent and differs on subsequent phases[8].

In 1981 Grol and colleagues showed how GPs can structure their contact with patients in order to prevent somatic fixation. They advised a systematic approach towards the problems raised and adequate management of the doctor-patient relationship. The latter means that the GP should give room to the patient, be clear about his/her own ideas and be a good chairman[9].

Recent developments in general practice are the concept of shared decision making in which patients' views and preferences about treatment options are discussed as well as transferring technical information about these options, and subsequently a shared decision may be made[10]. Outcome and effects of sharing decisions depends on sharing with whom, for example, GPs sharing decisions with urologists for lower urinary tract symptoms (LUTS) leads to medicalisation[11]. Sharing decisions may therefore have less desirable side-effects.

As described in the current models of Family Medicine[12] the cornerstone of general practice is patient-centred care. The future in general practice care stays oriented around patients, the new model focuses for example on a whole-person orientation, integrated care and ensured comprehensive care that is easy to access.

Over the years patients' ideas, concerns and expectations have always been important and became even more important, as well as patients' active role in the decision phase of the consultations. It is important to stress that GPs clinical competence in combination with his empathy are crucial for patient-centred care[4]. The patient-oriented approach is in all probability the key to effectiveness of health care, and should be seen in contrast to disease-oriented care[13].

As involvement is one of the current topics in modern general practice this thesis is focused on older patients' involvement in general practice care. The main part of this thesis is an integral part of a European collaborative project, called IMPROVE, which will be explained in more detail further on. Since there are only few studies for evidence of involvement of older patients, it is unclear to what extent older patients may want to be actively involved. We therefore decided to use a qualitative approach to explore the area of involving older patients. Secondly, on the basis of this exploration we used a quantitative approach to explore some promising interventions.

1.2 Older patients and their involvement in health care

As stated, people should be involved in decisions about their health care and about the design and delivery of their health care services[14;15]. Parallel to this, patients expect to be involved in their own care more and more[16], and they consider it one of the GP's responsibilities[17]. Additionally, involvement is an ethical principle and, in some countries, even a legal requirement[18]. Recognition of the need for patient involvement is therefore necessary[19;20]. In many countries professional bodies and public authorities launched policies to enhance the inclusion of patients' voices in clinical decision-making, quality improvement and health care planning.

The above statements apply to all patients, but what about the elderly in our society? Is their involvement in care as relevant and obvious as in other patient groups? We know that they are large consumers of health care[21] and that, in general, the population is ageing. So they form a large part of daily general practice care. It is unknown what older patients think of the above recommendations, and to what extent they have something to gain from involvement. Therefore key-questions for this thesis are what older patients and their GPs expect and prefer when it comes to involvement of older patients, and what suitable interventions are to improve involvement.

The interventions considered in this thesis are categorised as follows by Wensing and Grol[22] based on patients' views on health care:

- interventions focused on the use of health care (giving information on appropriate use of health care, giving information to choose a care provider),
- interventions focused on the preparation for contact with a care provider (supplying patient data, preparation for active participation),

- interventions focused on contact with the care provider (providing patient tailored information; stimulating the communication strategy of shared decision-making; stimulating patient adherence) and
- interventions focused on feedback of care (patients' evaluations of care and procedures used for complaints and comments).

1.3 Older patients

Ageing population and (co)morbidity

In 2000 almost seven per cent of the world's population was aged 65 years or older. By 2050 it is expected that this figure will have more than doubled[23]. A recent prognosis on population growth in the Netherlands shows that in 2040 23% of the total Dutch population will be 65 years or older, whilst now that is almost 14%[24].

Most developed countries have accepted the chronological age of 65 years as a definition of 'elderly' or older person. While this definition is somewhat arbitrary, it is often associated with the age at which one can begin to receive pension benefits.

(WHO 2003)

As a consequence of the ageing population, more attention has to be paid to the health problems and needs of older patients. Older patients often have multiple health problems, and their needs for care grow as they age. In previous studies figures vary, but approximately 80% of people older than 65 have one or more chronic conditions and 65% have multiple chronic conditions[25].

When the ten most common chronic diseases in general practice are considered (hypertension, obesity, chronic ischaemic heart disease, arthritis hip/knee, chronic respiratory disease, eczema, diabetes mellitus, hay fever, hyperlipidaemia and psoriasis) 34% of patients of 65 and older have none of these conditions, 27% are treated for one, 22% for two and 17% for three or more of these top ten chronic diseases[26]. It is expected that over the next 25 year a steady increase in chronic diseases is maintained[27]. This seems valid for the currently common morbidity, such as a stroke, heart failure, cataract, as well as for currently less common diseases, such as Parkinson's disease, prostate hypertrophia and glaucoma. It is expected that after 2030 the increase will level-off.

Osteoarthritis

Special attention in this thesis will be given to this chronic condition as an example of how to involve patients in case of a specific disease. Osteoarthritis (OA) is a highly prevalent disease amongst older people. It's most common locations are the knee and hip and it gives pain, functional limitations and instability, and may therefore be a reason for GP consultation. In older people arthritis symptoms are underreported[28]. This seems logical, as OA is not life threatening and patients therefore have a choice of consulting the GP or not. There are life-style improvements OA patients may adopt themselves to improve different symptoms, these life-style changes are for example, exercise[29-31], weight loss[32], and use of a walking aid. Therefore GPs are not always aware of their osteoarthritis patients' functional impairments, fear and depressive feelings[33]. When patients' involvement in OA care is improved this may improve patients' health outcome, such as functional status and mobility. On the contrary, there are risks of treatment of an in itself not life threatening condition like OA, for example the recent developments around the Coxibs. This highlights and emphasises the danger of medicalisation and the ratio of non-medication interventions.

1.4 Concepts

There is evidence that patients may gain from becoming involved. Active participation on the part of patients during the consultation is associated with better health outcomes[34;35]. Accumulating empirical studies show that patients of GPs who encourage them to participate more actively in treatment decisions have indeed more favourable health outcomes, in terms of both physiological and functional status, than those whose doctors do not[36]. This is probably strongly related with the evidence that because of involvement patients seem to be better able to adhere to prescribed medication and advice provided[37;38]. Besides these better health outcomes, patients' involvement may lead to enhanced satisfaction with care[39;40] and improved information sharing and patients' awareness of the issues involved[41].

On the other side, lack of involvement may have adverse consequences such as non-adherence to treatment, possibly with negative outcomes[42]. One increasingly recognises the fundamental importance of an older patient's dignity and autonomy[43]. This has two sides. One should always offer patients the opportunity to be(come) involved. However, some patients may not want to be(come) involved, and in this case one should respect someone's autonomy and we should therefore not force involvement.

Involvement

In attempts to define patient involvement, different terms have been used to describe similar concepts, such as patient participation, patient partnership, patient centredness and patient empowerment. All these strategies aim to improve the quality and effectiveness of consultations. To overcome the theoretical limitations of these different forms of patient involvement, in this thesis the global term 'patient involvement' is used to refer to concepts of 'enabling patients to take an active role in deciding about and planning their health care'[45]. Examples of methods for involving patients include: written materials (e.g. information leaflets about clinical conditions or questionnaires seeking patients' views on their care or symptoms), interactive communication skills (e.g. those used by the doctor in consultations with patients) or the use of a third person (relative, informal carer, nurse etc.) to help patients express their preferences. Involvement may be located at different levels[46]:

- involving patients in the development of medical care and
- involving patients in their own medical care.

This thesis focuses on the latter. This means supporting patients in deciding about using health care, facilitating the role of patients as their own health advocates and encouraging patients to share responsibility for their own health. Also the objective is to assist the patient to make a choice as informed as possible about the diagnosis and treatment, and about benefit and risk, and to take full part in a therapeutic alliance. The patient is able to exercise reasonable autonomy and share in the decisions for their medical treatment and care. The mutuality which originates from involvement is an achievement of both patients and doctors, and requires the active participation of patients in decisions regarding their care and situations[47].

What was known about preferences of older patients about their level of involvement at the start of our study? The research in this field was yet scarce. There were indications in the literature that older patients take a passive role during consultations, and are reserved in gaining resistance against the physicians' authority[48]. One could state that older patients have feelings of dependency on the physician[49;50]. They experience more difficulty in seeking and obtaining information during medical interviews[51;52] and consequently seemed to participate less in their consultations than other patients[36;53]. These experiences are undesirable: older patients in particular have large health care needs. This makes it imperative to improve support and health information to older people[54] in order to come to better involvement. As older patients' preferences in medical decision making seem to be rather passive and dependent on the general practitioner, it is important to understand the

background for this passive and dependent role. One might hypothesise that personal historical experiences play a role and that changing this is difficult. As this is important to know before one starts to expect older patients to be as involved as other patients, qualitative research is necessary to explore their ideas.

There is only limited evidence about GPs' preferences with respect to older patients' involvement. GPs are often the first care provider for older patients' health needs and problems. GPs, as well as patients, belong to different age cohorts that may influence their attitudes in consultations. There are some signs that age stereotypes may determine medical care provided to older patients.

In short, there may be room for older patients to profit more from their consultations. But does their current way of consulting leads to substantial problems in their care? In other words, is there a problem, or is this the way older people consult and is it satisfactory, or is there something to gain? Do older patients feel the need to improve their involvement in consultations with GPs? And if yes, are they then able to improve their consultations? The same seems to go for GPs, they may be rather dominant in consultations, and we do not know what their thoughts about involvement of older patients are. To explore older patients' and GPs' ideas in relation to such questions we performed a qualitative study in order to come to answers to the questions stated.

Self-management

Despite high morbidity in the older population, older patients may not seek help for specific complaints[55], thus health problems are underreported[56]. Being reluctant to seek care for complaints may be no problem provided that there is adequate self-management. Research in older patients' knowledge about their illness and treatment shows that a quarter does not know their medical condition[57] and a quarter makes errors in compliance to treatment[38]. To improve general practice care by improving self-management one should always be careful not to medicalise problems and (older) people, and therefore one of the aspects of self-management is the prevention of unnecessary treatment.

Involvement and self-management are closely related; both concepts suggest that individuals manage their own care. This 'self-management' refers to patient behaviour, which keeps illness under control and minimises its impact on health and quality of life. Optimal self-management may improve health outcomes as well as the efficiency of health care services and patient autonomy[58]. Taking wise decisions in seeking medical advice for a health

problem is an important aspect of self-management and an important role of the GP is to support this self-management in patients.

Involvement in health care, as a major common denominator of self-management, of older patients is not widespread[52;59]. What we do not know is whether patients with a strong self-management orientation may not (unjustly) seek advice for their health problems (underreported health problems), while those with a weak self-management orientation may seek advice for problems that do not necessarily need medical attention (frequent unjust attending). As both items, underreported health problems and frequent unjust attending, are leading to sub-optimal general practice care from a professional point of view. It could therefore be worthwhile to intervene in this process. But one should be careful to intervene in this balance, as this is a charming aspect of general practice care: not only the kind of problem leads to a consultation with a GP, but a lot of other aspects have a role in this; not every patient with the same problem consults his/her general practitioner. The risk of intervening in this balance is unnecessary treatment or care with possible negative side-effects. Therefore, to know if, when and where one should or may intervene we need more insight into self-management behaviour by older patients.

1.5 Interventions

There is a range of instruments to improve the involvement of patients in their health care[46]. Examples are questionnaires to assess patients' needs before a consultation with the doctor and surveys among patients to provide feedback to care providers. There is only scant information available on their effectiveness and implementation in everyday general practice, especially for older patients.

As stated before, in this thesis patient-focused interventions for patient-doctor contact and/or episodes of care are considered. A more detailed description of these interventions:

- Within the patient-clinician contact, patient involvement refers to activities of the doctor to enable the patient to be more actively involved in the consultation, and to activities of the patient to increase his or her involvement in the consultation. Such activities include the identification of patients' views on his or her health problem and treatment options, the provision of additional information or changed delivery of information according to the patients' expectations, and a more active participation in the decision-making[60]. An example is shared decision making on surgery, medication or watchful waiting with an older male patient with lower urinary tract

symptoms. Active involvement in the consultation may be regarded as the prerequisite to the creation of concordance between patient and doctor on the diagnosis and the most suitable treatment[61].

- Within the episode of care, patient involvement implies that the patient has a high level of self-management of the health problem. For instance, asthma patients or diabetes patients can be instructed to monitor their symptoms on a daily basis. Approaches include training programmes which enhance self-management and patient-held records[62].

Effectiveness

There is a lack of studies documenting the effects of enhancing patient involvement for older patients on a broad range of outcomes in daily practice. One study showed that a leaflet designed to increase the level of patient participation in consultations resulted in longer consultations with more question asking[63]. It is not clear to what extent such interventions are suitable for older patients as well[64].

Implementation

Not only the effects of specific methods should be studied, but also their actual uptake in health care. Doctors, patients and the public may lack competence or skills to use specific instruments, or have negative attitudes regarding specific approaches. For example, GPs can find that responding to patient requests for investigations generates negative feelings[65]; a study from the United States showed that informed decision making was often incomplete[66]; and when faced with conflict between the patient's right to self determination and the need to promote health, GPs tended to give health promotion higher priority[67].

Successful implementation of the instruments in general practice care requires effective patient involvement programmes, which are feasible for GPs and older patients. Such programmes should help to overcome potential barriers to implementation, such as the GPs' attitudes towards older people, the number of older people served by the general practice, the range of care providers involved in the care for older people, willingness of older people to co-operate with measurements and patient orientated consultation style of the doctor.

There may be cultural factors and different health care systems which have an influence on uptake[22]. It is therefore important to know which determinants related to implementation of patient involvement instruments are universal and which are country-specific. It can be expected that GPs' and patients' attitudes towards involvement of older people in general practice differ

between countries with strong consumer and older people's organisations than countries without those. Furthermore, the role of the GP in the care for older people varies across different European countries, which may influence the expertise and attitudes of care providers. An insight in this helps to develop successful implementation programmes and to develop effective policies to improve general practice care for older people.

International collaboration

An international perspective will show whether programmes to implement the instruments in clinical practice can be similar across countries or whether they should be adapted to the local conditions. Therefore, in the light of European unification in which health care will integrate as well, an international comparative study was set up to determine the relevance of different barriers and facilitating factors for implementation of patient involvement instruments, and the success of different implementation programmes. An additional advantage of this international study was that patients and GPs could benefit from experiences in other places in Europe as these were shared in this international project. European countries with different health care systems and cultures were included in this study.

In conclusion, the opportunities and threats of an older patient's involvement are not clear. Neither are the strenghts and weaknesses of available interventions in this respect. Before we create expectations of involving older patients in their care, there is a need to explore this area broadly, in order to come to statements about older patients and their involvement in health care. We therefore designed three related studies in which we try to formulate answers to the asked questions. As it is important to know the barriers and facilitating factors towards involvement of older patients and GPs, we first designed interview studies in which we explored this area. Second, on the basis of the outcomes of these interviews and a review of the literature, patient involvement methods were pilot-tested. Third, with the experience of the pilot-study in mind, we designed a patient involvement implementation programme which was evaluated more quantitatively. The implementation programme included the findings of the previous studies. In addition, we designed a study on self-management as a disease-specific outgrowth of the previous. We chose osteo-arthritis; as this disease is highly prevalent; has an impact on daily life; gives patients freedom in visiting a GP or not; benefits from self-management and in which professional care has risks.

With a group of GPs and researchers from eleven countries we performed the studies referred to in chapters 2-4 and chapters 7 and 8. This research project was named IMPROVE and had the following aims:

- to identify barriers and facilitators for involving patients in their general practice care,
- to identify instruments for improving the involvement on patients in general practice,
- to examine the feasibility of these instruments in daily general practice,
- to provide programmes for improving involvement of patients in general practice.

1.6 Research questions of this thesis

Chapter 2	What are older patients' thoughts of positive and negative consequences of involvement in their GP care and what are the barriers and facilitators they perceive?
	What are older patients' views towards different methods that support their involvement?
Design	Qualitative study
Chapter 3	What are GPs' thoughts of positive and negative consequences of involvement of older patients and what are the barriers and facilitators they perceive?
Design	Qualitative study
Chapter 4	What are differences between GPs and older patients in barriers and facilitators to using patient information leaflets and patient satisfaction questionnaires as patient involvement instruments in general practice care?
	Are there country-specific differences in this respect?
Design	Qualitative study
Chapter 5	What influence do self-management orientations and perceptions of health problems have in older adults on their tendency to seek medical care?
Design	Population based prospective cohort study
Chapter 6	What is known about interventions aimed at improving an older patient's involvement in his/her own primary care?
Design	Systematic review of literature
Chapter 7	What are changes in older patients' perceived quality of general practice care after implementing a programme to enhance their involvement general practice consultations?
Design	Uncontrolled before-after study
Chapter 8	What are the effects of a consultation leaflet implementationprogramme on patients' evaluations of their care?
	Do patients with underreported health problems benefit from our implementation programme by discussing more known underreported health problems?
Design	Cluster randomised controlled trial
Chapter 9	What are the effects of a self-management intervention on an older osteoarthritis patient's health status and mobility?
Design	Randomised controlled trial

1.7 Content of this thesis

In the explorative part of this thesis (chapter 2-5) we aimed to identify older patients' and GPs' views on older patients' involvement and self-management in their general practice care. We identified barriers and facilitators to their involvement and asked them about different interventions that aimed to improve involvement. Subsequently the intervention part of this thesis starts with a systematic review of the literature (chapter 6) about interventions to improve older patients' involvement in their care. Chapters 7 and 8 describe respectively an evaluation programme and a randomised trial about a consultation leaflet implementation programme. Chapter 9 describes a disease specific variant of this implementation programme. Chapter 10 contains the discussion and the main conclusions of our studies.

References

1 Green LA, Fryer Jr GE, Yawn BP, Lanier D, Dovey SM. The ecology of medical care revisited. N Engl J Med 2001; 344:2021-5.

2 White KL, Williams TF, Greenberg BG. The ecology of medical care. N Engl J Med 1961; 265:885-92.

3 van de Lisdonk EH. Perceived and presented morbidity in general practice. A study with diaries in four general practices in The Netherlands. Scand J Prim Health Care 1989; 7:73-8.

4 van Os TW, van den Brink RH, Tiemens BG, Jenner JA, van der MK, Ormel J. Communicative skills of general practitioners augment the effectiveness of guideline-based depression treatment. J Affect Disord 2005; 84:43-51.

5 Balint M. The Doctor, His Patient and The Illness. 1957.

6 Helman CG. Disease versus illness in general practice. J R Coll Gen Pract 1981; 31:548-52.

7 Becker MH, Maiman LA. Sociobehavioral determinants of compliance with health and medical care recommendations. Med Care 1975; 13:10-24.

8 Byrne PS, Long BEL. Doctors talking to patients. RCGP, 1976.

9 Grol R. To heal or to harm. RCGP, 1981.

10 Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract 1999; 49:477-82.

11 Wolters R, Wensing M, Klomp M, van Weel C, Grol R. Shared care and the management of lower urinary tract symptoms. BJU Int 2004; 94:1287-90.

12 Task F, Green LA, Graham R, Bagley B, Kilo CM, Spann SJ, et al. Task Force 1. Report of the Task Force on Patient Expectations, Core Values, Reintegration, and the New Model of Family Medicine. Ann Fam Med 2004; 2:S33-S50.

13 Starfield B. Is US Health Really the Best in the World? JAMA 2000; 284:483-5.

14 Weiss SJ. Consensual norms regarding patient involvement. Soc Sci Med 1986; 22:489-96.

15 Williams B. Patient satisfaction: a valid concept? Soc Sci Med 1994; 38:509-16.

16 Verhoef MJ, White MA, Doll R. Cancer patients' expectations of the role of family physicians in communication about complementary therapies. Cancer Prev Control 1999; 3:181-7.

17 Buetow S. The scope for the involvement of patients in their consultations with health professionals: rights, responsibilities and preferences of patients. J Med Ethics 1998; 24:243-7.

18 Coulter A, Elwyn G. What do patients want from high-quality general practice and how do we involve them in improvement? Br J Gen Pract 2002; 52:S22-S26.

19 Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract 1999; 49:477-82.

20 Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. BMJ 2002; 325:1263.

21 Fryer GE Jr, Green LA, Dovey SM, Yawn BP, Phillips RL, Lanier D. Variation in the ecology of medical care. Ann Fam Med 2003; 1:81-9.

22 Wensing M, Grol R. Patients' views on health care. Dis Manage Health Outcomes 2000; 7:117-25.

23 United Nations, Population Division, and Department of Economic and Social Affairs. Population ageing 2002. Second World Assembly on Ageing. 2002.
24 de Jong A. Bevolkingsprognose 2000-2050: bevolking groeit tot 18 miljoen. Mndstat bevolking (CBS) 2001; 49:22-5.
25 Wolff JL, Starfield B, Anderson G. Prevalence, Expenditures, and Complications of Multiple Chronic Conditions in the Elderly. Arch Intern Med 2002; 162:2269-76.
26 van Weel C. Chronic diseases in general practice: the longitudinal dimension. Eur J Gen Pract 1996; 2:17-21.
27 van Weel C, Lagro-Janssen T, van de Lisdonk E, Bakx C, van den Hoogen H, Bor H, et al. Future trends in morbidity in general practice: the limitations of biomedical factors. Zdrav Var 2003; 42:51-7.
28 Kriegsman DM, Penninx BW, van Eijk JT, Boeke AJ, Deeg DJ. Self-reports and general practitioner information on the presence of chronic diseases in community dwelling elderly. A study on the accuracy of patients' self-reports and on determinants of inaccuracy. J Clin Epidemiol 1996; 49:1407-17.
29 Minor MA, Hewett JE, Webel RR, Anderson SK, Kay DR. Efficacy of physical conditioning exercise in patients with rheumatoid arthritis and osteoarthritis. Arthritis Rheum 1989; 32:1396-405.
30 Penninx BW, Rejeski WJ, Pandya J, Miller ME, Di Bari M, Applegate WB, et al. Exercise and depressive symptoms: a comparison of aerobic and resistance exercise effects on emotional and physical function in older persons with high and low depressive symptomatology. J Gerontol B Psychol Sci Soc Sci 2002; 57: 124-32.
31 van Baar ME, Dekker J, Oostendorp RA, Bijl D, Voorn TB, Lemmens JA, et al. The effectiveness of exercise therapy in patients with osteoarthritis of the hip or knee: a randomized clinical trial. J Rheumatol 1998; 25:2432-9.
32 Felson DT, Chaisson CE. Understanding the relationship between body weight and osteoarthritis. Baillieres Clin Rheumatol 1997; 11:671-81.
33 Memel DS, Kirwan JR, Sharp DJ, Hehir M. General practitioners miss disability and anxiety as well as depression in their patients with osteoarthritis. Br J Gen Pract 2000; 50:645-8.
34 Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989; 27:S110-S127.
35 Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE. Characteristics of physicians with participatory decision-making styles. Ann Intern Med 1996; 124:497-504.
36 Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. Med Care 1995; 33:1176-87.
37 Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998; 36:1138-61.
38 Blenkiron P. The elderly and their medication: understanding and compliance in a family practice. Postgrad Med J 1996; 72:671-6.
39 Rodin J. Aging and health: effects of the sense of control. Science 1986; 233:1271-6.
40 Lewis JR. Patient views on quality care in general practice: Literature review. Soc Sci Med 1994; 39:655-70.

41 Liaw ST, Radford AJ, Maddocks I. The impact of a computer generated patient held health record. Aust Fam Physician 1998; 27:S39-S43.
42 Bikowski RM, Ripsin CM, Lorraine VL. Physician-Patient Congruence Regarding Medication Regimens. J Am Geriatr Soc 2001; 49:1353-7.
43 Lothian K, Philp I. Care of older people: Maintaining the dignity and autonomy of older people in the health care setting. BMJ 2001; 322:668-70.
45 Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. Eur J Gen Pract 2003; 9:62-5.
46 Wensing M, Grol R. What can patients do to improve health care? Health Expect 1998; 1:37-49.
47 Gafaranga J, Britten N. "Fire away": the opening sequence in general practice consultations. Fam Pract 2003; 20:242-7.
48 Beisecker AE. Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. Gerontologist 1988; 28: 330-5.
49 Smith RA, Woodward N, Wallston B, Wallston K, Rye P, Zylstra M. Health care implications of desire and expectancy for control in elderly adults. J Gerontol 1988; 43:1-7.
50 Woodward N, Wallston B. Age and health care beliefs: self-efficacy as a mediator of low desire for control. Psychol Aging 1987; 2:3-8.
51 Breemhaar B, Visser AP, Kleijnen JG. Perceptions and behaviour among elderly hospital patients: description and explanation of age differences in satisfaction, knowledge, emotions and behaviour. Soc Sci Med 1990; 31:1377-85.
52 Rost K, Frankel R. The introduction of the older patient's problems in the medical visit. J Aging Health 1993; 5:387-401.
53 Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. Ann Intern Med 1980; 92:832-6.
54 Callahan EJ, Bertakis KD, Azari R, Robbins JA, Helms LJ, Chang DW. The influence of patient age on primary care resident physician-patient interaction. J Am Geriatr Soc 2000; 48:30-5.
55 Foster J, Dale J, Jessopp L. A qualitative study of older people's views of out-of-hours services. Br J Gen Pract 2001; 51:719-23.
56 Brown K, Boot D, Groom L, Williams E. Problems found in the over-75s by the annual health check. Br J Gen Pract 1997; 47:31-5.
57 Radhamanohar M, Than M, Rizvi S. Assessment of patients' knowledge about their illness and treatment. Br J Clin Pract 1993; 47:23-5.
58 Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. JAMA 2002; 288:2469-75.
59 Tennstedt SL. Empowering older patients to communicate more effectively in the medical encounter. Clin Geriatr Med 2000; 16:61-70, ix.
60 Bekker H, Thornton JG, Ariey CM, Connelly JB, Hewison J, Robinson MB, et al. Informed decision making: an annotated bibliography and systematic review. Health Technol Assess 1999; 3(1).
61 Britten N, Stevenson FA, Barry CA, Barber N, Bradley CP. Misunderstandings in prescribing decisions in general practice: qualitative study. BMJ 2000; 320: 484-8.
62 Dickey LL. Promoting preventive care with patient-held minirecords: a review. Patient Educ Couns 1993; 20:37-47.

63 McCann S, Weinman J. Empowering the patient in the consultation: a pilot study. Patient Educ Couns 1996; 27:227-34.
64 McCormick WC, Inui TS, Roter DL. Interventions in physician-elderly patient interactions. Res Aging 1996; 18:103-36.
65 Cohen O, Kahan E, Zalewski S, Kitai E. Medical investigations requested by patients: how do primary care physicians react? Fam Med 1999; 31:426-31.
66 Braddock CH, Edwards KA, Hasenberg NM, Laidley TL, Levinson W. Informed decision making in outpatient practice: time to get back to basics. JAMA 1999; 282:2313-20.
67 Bremberg S, Nilstun T. Patients' autonomy and medical benefit: ethical reasoning among GPs. Fam Pract 2000; 17:124-8.

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Section I

Exploration of older patients' and GPs' views on involvement

Older patients' views on their involvement in general practice consultations: an interview study

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Richard Grol

Ouderen over hun rol in het huisartsenconsult: een interviewstudie.
TSG 2005; 83(2):93-97

2

Abstract

Objective

To identify positive and negative expectations of, and barriers and facilitators to involvement of older patients in their general practice care.

Methods

Semi-structured interviews with 28 older patients (70 years and older) in the region of Nijmegen, the Netherlands. Patients from different subgroups were included.

Results

Older patients have positive expectations to becoming involved. However, they identified barriers to involvement such as not being used to become involved; feeling themselves lay persons in consultations; being nervous during consultations; and having cognitive and physical impairments. Also the GP who has a lack of time and sometimes a lack of attention was mentioned as a barrier. Besides this, anxiousness of taking the wrong decisions or suddenly becoming more responsible for decisions was what older patients kept away from becoming more involved. A number of facilitators to involvement were mentioned: taking a family member or friend to the consultation; preparing the consultation by writing down questions for the GP; and a personal GP with enough attention and a stimulating attitude.

Discussion

Older patients have, besides positive expectations, some worries about involvement in their own general practice care. Enhancing their involvement will need a gradual stimulation. GPs may have a role in this, by taking some of older patients' worries away.

Introduction

According to recent population prognoses, senior citizens (65+) will account for 23% of the entire Dutch population around 2040, compared to close on 14% now[1]. As one's age increases, the need for care increases as well. The question is how to go about meeting this increasing need for medical care. Signs can be observed in society that emphasise the value of the active participation of patients in the care process, including more responsibility[2;3]. An active contribution on the part of patients could result in improving the degree to which they adhere to therapy and advice; more satisfaction regarding the care that is provided; and could possibly be beneficial to their health as well[4-6]. GPs are favourable to an active participation of the elderly where it concerns care[7], yet the elderly currently receive less support and health counselling than do youths[8]. This might explain why one fourth of the elderly people are not well acquainted with their illnesses and medication[9].

The preferences of the elderly concerning their role in the care that is provided by general practitioners are partially known. A recent review shows that older people prefer a dominant (more traditional) doctor, they also consider continuity in care by means of the same doctor to be important and they have a stronger preference for a wait-and-see policy[10]. There is furthermore some evidence in the literature that many older people adopt a passive role during visits to a doctor, that they are reticent both about taking responsibility for medical decisions[11], as well as about offering resistance to the authority of the doctor[12]. In addition, some literature suggests that older people's preference for information is stronger than being allowed to contribute to decisions[13].

In short, it appears it would be profitable to stimulate the elderly to actively participate in the care that is provided by GPs. But some older people find this difficult and it hardly happens in practice.

The purpose of this study is to gather practical ideas that will facilitate the active participation of the elderly with respect to their general practice care. Various concepts have been described to support patients' involvement; we use the concept in which involvement of patients in their care is regarded as making it possible for older people to adopt an active role in making decisions about and planning the care that is provided by their GPs[14]. A multitude of instruments for the purpose of encouraging patients' involvement has been described[15]. If we are familiar with the obstacles that prevent a more active contribution of the elderly, then it may be possible to develop strategies or instruments that overcome these obstacles.

The following research questions applied:

- What are the positive and negative expectations of the elderly concerning their involvement during doctor consultations?
- What are facilitators for the elderly to participate in the consultation more actively and what are barriers to this participation?
- What is the opinion of the elderly of a set of instruments that could support their involvement?

Methods

In order to answer the research questions, we opted for an exploratory, qualitative research design involving semi-structured interviews. The interview was tested on two older patients in terms of workability and comprehensibility. This test gave reason to make a few minor adjustments. The interview consisted of open questions concerning the anticipated pros and cons and the barriers and facilitating factors, if any, regarding an active participation in the care provided (Box 1). In addition, we asked similar questions concerning a set of instruments (a patient information leaflet on hypertension and a patient-satisfaction questionnaire[16]) that are to promote participation. Depending upon the answers that were given, the interviewers continued to ask questions, so as to gain a clear picture of the patient's opinion. The interviewers stuck to the original order of the questions as much as possible. We defined patient involvement in care as follows: making it possible for patients to adopt an active role in planning and making decisions regarding their general practice care. Examples of methods to enhance patient involvement include: written patients' information, patient-satisfaction questionnaires, communication styles of the GP and bringing along, for example, a family member to the visit to the doctor.

Box 1 Interview - general questions

1. What do you think about the idea of involving people more in their health care (decisions)?
2. How much do you feel your GP involves you in your care?
   a. What could your GP do to improve your involvement?
3. In general, how do you (would you) feel about being involved by your GP?
   a. What are (would be) the benefits?
   b. What are (would be) the difficulties?

Study Population

We asked three GPs in the vicinity of Nijmegen to each request ten older patients (70 years old or older) to participate in the study. The GP determined whether or not one was able to take part in an interview. Our aim was to achieve an equal number of men and women and to work with patients between the age of 70 and 80 and older than 80. In order to gain an impression, as adequately as possible, of the ideas of the elderly, we defined four groups of characteristics of which it is assumed that they might influence one's ideas regarding participation[17] (patients with an isolated illness-episode, patients with a known chronic illness, patients with a life threatening disease and non-attenders). In addition to the criteria of age and sex, we instructed the GPs on using a selection table to obtain an equal distribution of patients between these four groups.

Analysis

The interviews were conducted at the patients' homes; the interview generally required a total of a half-hour. The interviewers (RW, MdK) introduced themselves as independent researchers and made audio recordings of the entire interview. The interviews were then written out word for word. The same researchers then composed a list of codes that was based on a content analysis of the first ten interviews. The codes covered the subjects of the research questions, meaning the anticipated pros and cons and the barriers and facilitating factors pertaining to the patient's involvement. In addition, the researchers also allocated codes to the pros and cons of the two instruments. Using Atlas.ti software, they assigned codes in the interviews independent of one another. The two researchers then compared the codes and discussed the differences until they could reach a consensus. All of the interviews were double-coded. The statements on the part of the elderly participants were grouped per code and, if possible, combined within one theme. The themes are described in the paragraph regarding the results.

Results

Of the patients that were selected by the general practitioners (a total of 36), 28 eventually agreed to the interview. As previously explained, our study included older persons from all of the desired categories (Table 1).

Table 1 Patient characteristics (absolute numbers)

	70-80		80+		Total
	Male	Female	Male	Female	
Isolated illness	0	2	2	0	4
Chronic illness	4	3	3	2	12
Life threatening illness	0	3	1	2	6
Non-attenders	2	1	1	2	6
Total	6	9	7	6	28

Positive expectations

The elderly indicated to consider the GP a confidant. They expect to be able to increase this degree of trust through a more active contribution on their part. Some of the elderly indicated to feel more at ease when decisions were made together with the doctor, and they believed that they would perhaps be more inclined to stick to the proposed therapy.

> *I appreciate being involved, it allows me to form an idea of what is going on, I can then rest easy, and no longer make up things in my mind (Patient 9)*

The increase of knowledge regarding an illness and its treatment was also viewed as a positive expectation of a higher degree of participation.

Negative expectations

Some of the elderly persons indicated that they preferred not to know too much. A more prominent role during the consultation, which involved that they would receive more information from the GP, made some of them nervous for the consultation and they expected to feel anxiety about missing important issues.

> *Perhaps there is also a certain fear of being well-informed. I wonder what is the matter, and it might be better not to mention it, a lot of people experience that fear (Patient 25)*

> *I am so nervous, that I forget everything. I simply do not dare to listen, or I forget (Patient 24)*

In addition, some indicated that they did not feel it was wise to think along with the doctor and to ask a lot of questions, because they considered themselves incompetent.

> *You want to stay healthy, of course, but to claim that you yourself can best judge what is best for you, well, that could prove to be a dangerous form of impertinence (Patient 8)*

One or two indicated that GPs generally stick to their own plan anyway, and so they did not expect much from being allowed to participate.

Barriers

The reasons why the elderly would prefer not to be involved are divided into general practitioner-related and patient-related obstacles. The patient-related obstacles involved the fact that a number of older persons indicated that they were not all that curious to know all sorts of information and backgrounds concerning the symptoms. They are not used to being well-informed and having a say, and so it did not seem logical to them if this should be the case.

> *The older group is not all that curious to hear the doctor's line of reasoning upon formulating his diagnosis (Patient 25)*

In addition to not feeling inclined to meddle in matters that one is not familiar with, some of the interviewees found it difficult to contribute in a medical sense. As a result, the doctor's decision was often considered the decisive factor. The fact that they looked up to the doctor and found it difficult to follow his/her line of reasoning during the consultation also played an important role in this respect. If the doctor did not encourage them to ask questions, then they would simply wait and see what would happen.

> *We used to look up to the doctor a lot and we scarcely dared ask any questions. We still tend to do that (Patient 28)*

A number of the elderly interviewees felt tense before and during a consultation with a doctor. This, together with a poor memory, loss of concentration and poor hearing, was considered an obstacle. In addition, a number of the elderly persons indicated that they expected adequate treatment without personally contributing to the care process. Finally, some of the elderly stated to live alone and that they are therefore inclined to solve their own problems and less inclined to bother the GP in that respect.

The GP-related obstacle that was mentioned most often concerned the fact that the GP can sometimes appear to be (too) casual. The consultation is brief, the GP does not appear to pay adequate attention in some cases and the patient sometimes wonders whether or not the GP is actually listening.

> *...half of his attention focused on the computer, is he listening or not, it is like you don't even count ... (Patient 1)*

Facilitators

The most important factor in ensuring that one has an adequate say in their care process is bringing an acquaintance or family member along on the visit to the doctor. This because this person can be supportive when the patient has questions and it is easier to go over everything that was said when one is home later on. Another stimulating factor that was mentioned concerned writing down questions prior to the consultation with the GP, partly because this meant that one had to reflect upon the situation beforehand.

Other stimulating factors concern the GP asking questions, paying attention to you and making a spontaneous house call every once in a while or making an appointment for a yearly medical check-up.

> *If he never says anything or asks anything, then I just clam up completely. But because he does ask questions, you can somewhat relax (Patient 9)*

This personal approach on the part of the GP was found to be important where it concerned contributing to the care process. For example, a number of the elderly value their own doctor and indicated that young doctors adopt a different approach. The elderly also found honesty and openness in the contact with the GP to be characteristic of a personal approach.

Patient information leaflet

The elderly indicated to find the leaflets useful, as they can then read up on what the problem is when they are at home. In their opinion, this led to a clearer understanding of the situation and they indicated that they would perhaps be better prepared for the next consultation. In addition, they appreciated the fact that the leaflets explained what they could do themselves towards improving their disorder. Concerning the disadvantages of the leaflets, the elderly indicated that the leaflets were difficult to understand for some, that a lack of understanding can lead to fear and that the number of leaflets that is available is so high that it is difficult to find one's way in this.

Patient-satisfaction questionnaire

The older interviewees indicated that, by completing a concrete list of questions, they gained a better understanding of the aspects that play a role in the job responsibilities of the GP. In addition, the GP is provided with information that can be used to improve certain matters in his/her own practice. However, the list was found to be long and difficult; assistance in completing the questionnaire was appreciated.

Discussion

The findings of our study are not univocal. Some of the elderly had positive expectations concerning an active role in the consultation with the GP. However, an active contribution on their part is not yet customary in current practice. This is partly intrinsic to the wait-and-see and modest attitude on the part of some of the elderly in their contact with the GP. In addition, some of the older interviewees look forward to increased involvement with apprehension. However, the elderly who do feel positive towards actively contributing still also experience a number of obstacles.

A number of the obstacles that are put forward have been previously mentioned in the literature. Such as the difference in the level of education that may exist between the patient and the doctor[18;19] and the effects of sensory and cognitive limitations that are sometimes present[20]. In the literature, the degree of anxiety and unaccustomedness during doctor consultations that is described by the elderly is often linked to the degree of being ill[21].

If one considers the conditions for involvement, then the older participants in our study, as do the elderly in a previous questionnaire study[22], confirm the importance of a good relationship with the GP and the fact that the personal interest and an attentive and stimulating attitude on the part of the doctor is desired. This seems to be the bare essential for older patients' involvement. In addition, being well prepared for the consultation, by writing down questions for example, may be useful. However, conclusive evidence to that effect has never been found[23]. Taking a family member along to the consultation may increase one's contribution as well; this occurs in a small percentage of the contacts[24;25]. In these contacts, the family member helps the older person with asking questions and they support the information that is to be given to the doctor[25].

This interview study using three selected groups of patients from three practices has a number of limitations. There may be some bias concerning the selection of the patients, but we are of the opinion that the various subgroups within the total group of older persons are all well represented due to a careful stratification. However, by selecting the older patients of only three GPs, the results may be somewhat distorted.

It can be concluded that older people appear not to be unfavourable towards a more active role in their general practice care. However, it appears it would be best to gradually stimulate a higher level of involvement. If older patients are thrown in at the deep end, they may become increasingly worried about their own actions and that would be an undesired consequence of involvement.

This can be overcome by largely leaving the initiative of contributing more actively to the older person him/herself.

In addition, a more active role is not something that should be pursued for all elderly people in each and every situation. An important question for subsequent studies is which older persons will profit from a more active role and how to get in contact with these people. The seriousness of the illness, a lower income, a lower professional level and a higher age, for example, are linked to a passive, dependent attitude in the literature[17].

If the GP were to remove a number of the obstacles and negative expectations as described in this study, then it may be easier for older people to say what they want to say during the consultation. The concern on the part of the elderly as mentioned above that they will have to reach decisions on their own is, for example, important in this respect.

In view of the results of this study, there now seems to be room for testing the effectiveness of a number of instruments for the purpose of supporting the elderly, such as a list that can be completed prior to the consultation regarding the items and any questions for the doctor.

References

1 de Jong A. Bevolkingsprognose 2000-2050: bevolking groeit tot 18 miljoen. Mndstat bevolking (CBS) 2001; 49:22-5.
2 Mulder JH. Stille revolutie onder patiënten. Med Contact 2001; 56:1545-7.
3 The BAM. Gedeelde zorgen. Med Contact 2000; 55:1485-8.
4 Blenkiron P. The elderly and their medication: understanding and compliance in a family practice. Postgrad Med J 1996; 72:671-6.
5 Rodin J. Aging and health: effects of the sense of control. Science 1986; 233:1271-76.
6 Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998; 36:1138-61.
7 Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R. GPs' views on involvement of older patients: an European qualitative study. Patient Educ Couns 2004; 53:183-8.
8 Callahan EJ, Bertakis KD, Azari R, Robbins JA, Helms LJ, Chang DW. The influence of patient age on primary care resident physician-patient interaction. J Am Geriatr Soc 2000; 48:30-5.
9 Radhamanohar M, Than M, Rizvi S. Assessment of patients' knowledge about their illness and treatment. Br J Clin Pract 1993; 47:23-5.
10 Jung HP, Baerveldt C, Olesen F, Grol R, Wensing M. Patient characteristics as predictors of primary health care preferences: A systematic literature analysis. Health Expect 2003; 6:160-81.
11 Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med 1999; 17:285-94.
12 Beisecker AE. Aging and the desire for information and input in medical decisions: patient consumerism in medical encounters. Gerontologist 1988; 28: 330-5.
13 Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract 1999; 49:477-82.
14 Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. Eur J Gen Pract 2003; 9:62-5.
15 Wensing M, Grol R. What can patients do to improve health care? Health Expect 1998; 1:37-49.
16 Grol R, Wensing M, Mainz J, Jung HP, Ferreira P, Hearnshaw H, et al. Patients in Europe evaluate general practice care: an international comparison. Br J Gen Pract 2000; 50:882-7.
17 Roter DL. The outpatient medical encounter and elderly patients. Clin Geriatr Med 2000; 16:95-107.
18 Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. Med Care 1995; 33:1176-87.
19 Waitzkin H. Information giving in medical care. J Health Soc Behav 1985; 26: 81-101.
20 Adelman RD, Greene MG, Ory MG. Communication between older patients and their physicians. Clin Geriatr Med 2000; 16:1-24, VII.

21 Hall JA, Roter DL, Milburn MA, Daltroy LH. Patients' health as a predictor of physician and patient behavior in medical visits. A synthesis of four studies. Med Care 1996; 34:1205-18.
22 Jung HP, Wensing M, Grol R. Wat vinden patiënten belangrijk? Aspecten van huisartsgeneeskundige zorg, gezien vanuit het perspectief van de patiënt. Huisarts Wet 1996; 39:594-9.
23 Tennstedt SL. Empowering older patients to communicate more effectively in the medical encounter. Clin Geriatr Med 2000; 16:61-70, IX.
24 Glasser M, Prohaska T, Roska J. The role of the family in medical care-seeking decisions of older persons. Fam Community Health 1992; 15:59-70.
25 Silliman RA, Bhatti S, Khan A. The care of older persons with diabetes mellitus: Families and primary care physicians. J Am Geriatr Soc 1996; 44:1314-21.

GPs' views on involvement of older patients: a European qualitative study

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3

Abstract

Involvement of older patients in general practice care is regarded as important, but is not widespread. To determine specific barriers to the involvement of older patients in general practice care and to identify variations between countries, we performed an international comparative study based on qualitative interviews with 233 general practitioners (GPs) in 11 countries.

Most GPs thought that involving older patients had positive outcomes. GPs saw patient involvement as a process taking place solely during consultations. The main barrier for GPs was lack of time. Barriers related to older patients were their feelings of respect for doctors, their lack of experience in being involved and possible mental and physical impairments.

To conclude, increasing involvement of older patients is not easy and will only be effective when GPs have adopted a more developed concept of patient involvement and are supported with the different methods for achieving this. The range of appropriate interventions may be similar in all countries.

Introduction

In response to population ageing[1], health care policy emphasises the importance of involving older patients in the planning and delivery of health care[2;3]. However, older people may be reluctant to seek help for their complaints[4], they experience more difficulty in seeking and obtaining information during medical interviews[5;6] and participate less in their consultations than other patients[7], even though they often have multiple health problems. Promoting involvement of older patients may improve the quality of care leading to better adherence with prescribed medication and advice provided[8], higher satisfaction with care and improvement in health status[9]. General practitioners (GPs) themselves think that involvement of patients is important[10]. Despite the different methods for involving patients[11], involvement of older patients is not widespread[6;12]. The reasons behind this contrast are unclear. Potential explanations are that GPs do not have enough time in consultations, they may lack concrete skills or ideas for achieving involvement of their older patients, or they think that older patients do not want to be involved. The factors that influence effective implementation of involvement of older patients may depend on cultural factors and health care systems, and consequently there may be differences between countries[13]. In order to gain more insight into relevant barriers, we performed an international study, which aimed to identify GPs' thoughts of positive and negative consequences of involvement of older patients and the barriers and facilitators they perceive.

Methods

We performed a qualitative interview study in 11 countries, as part of a larger international research project[14].

Participants

The participating countries were Austria, Belgium, Denmark, England, France, Germany, Israel, The Netherlands, Portugal, Slovenia and Switzerland. In order to obtain a typical cross-section of GPs, we sought a heterogeneous sample of at least 20 GPs in each country, stratified by age (≤45 years versus >45 years), gender and level of urbanisation (urban practice, rural practice and city practice), during autumn 2000. GPs who cared for no older patients (>70 years) or GPs who only cared for older patients were excluded.

Interviews

The co-ordinating research group in England developed a semi-structured interview schedule, which was adapted jointly by the researchers of all collaborating countries. After tests of the interview-format in all countries, a final interview schedule was agreed upon by researchers from these countries. In the interviews, GPs were asked about what they thought patient involvement was, and about advantages, barriers and facilitators of involvement of older patients. Subsequently they were provided with our definition of patient involvement (Box 1). Interviews took on average 30 minutes. Interviewers in each country were trained, and the interviews were tape recorded and transcribed verbatim for analysis.

Box 1 Definition of patient involvement

Patient involvement is defined in this study as enabling patients to take an active role in deciding about and planning their care. Examples of methods to increase patient involvement include:

- Written materials, such as information leaflets about clinical conditions, or questionnaires to seek patients' views on their care or symptoms.
- Communication skills such as those used by the doctor in consultation with patients.
- Use of a third person (relative, nurse, etc.) to help patients express their preferences.

Data analysis

A code list was devised through consensus discussions at a meeting of the collaborators from each country. This code list was based on a detailed content analysis of half of all GP interviews from four countries (Belgium, Germany, The Netherlands, Slovenia). It contained 37 codes, which classified GPs' ideas about patient involvement, and the barriers, facilitators and advantages of patient involvement.

Researchers in each country then studied their transcripts systematically to look for the presence of quotations related to codes from this code list, using Atlas software[15]. Subsequently, the quotations from all participating countries were gathered by code and studied independently in detail by two authors (Wetzels and Geest) to achieve a better understanding of GPs' answers in the different countries. Through consensus discussions key themes were defined on the basis of the codes and corresponding quotations. The same two authors independently selected which key themes were representative for which

country. Finally, the researchers from each country were asked to confirm these themes for their own countries. The researchers checked the key themes and gave additional quotations.

In each country, consistent application of coding was ensured by two researchers coding at least five interviews independently, and discussing differences until consensus was reached. International consistency in coding was achieved by translating a coded interview from each country into English, which was then coded independently by the English researcher, the level of agreement between each country and the English researcher being assessed. No important differences in coding were found.

Results

In nine countries, stratification was achieved according to the sampling plan, except for Denmark and France, which included 15 and 16 GPs, respectively. Three audio tapes in Denmark were of poor quality and had to be excluded. In total, 233 GPs were interviewed, of whom 96 were female (41, 2%). GPs above 45 years and GPs in city practices were slightly over represented (Table 1). Table 2 gives a schematic overview of GPs' opinions about the different topics around involvement of older patients.

Table 1 Characteristics of GPs (absolute numbers)

Country	Age		Gender		Practice			Total
	≤45	>45	Male	Female	City	Urban	Rural	
France	5	11	12	4	5	8	3	16
Austria	7	13	11	9	9	5	6	20
Belgium	13	13	18	8	15	6	5	26
Switzerland	6	14	14	6	9	3	8	20
Germany	11	14	15	10	10	6	9	25
Israel	11	11	12	10	12	4	6	22
Portugal	12	11	9	14	10	8	5	23
Slovenia	13	13	12	14	11	7	8	26
England	10	13	18	5	4	7	12	23
Denmark	6	6	5	7	4	4	4	12
Netherlands	10	10	11	9	7	6	7	20
Total	104	129	137	96	96	64	73	233
	(44,6%)	(55,4%)	(58,8%)	(41,2%)	(41,2%)	(27,5%)	(31,3%)	

Table 2 Overview of themes

Themes	Number of countries in which theme was mentioned (max: 11)	Theme not present in:[a]
GPs' ideas of patient involvement		
Explaining and informing patients about health aspects	11	
Making decisions together with patients	10	F
Patients taking responsibility for their involvement	10	F
GPs giving patients the opportunity to ask questions	9	D, I
Positive outcomes of patient involvement		
Acceptance of advice and adherence to medication	11	
Improved patient satisfaction	11	
Improved GP satisfaction	8	B, I, S
Equivalent division of responsibilities	8	B, F, N
Negative outcomes of patient involvement		
Anxious towards patient involvement	9	B, F
Barriers of patient involvement		
Organisational aspects (lack of time, and/or resources)	11	
Patient related		
Acceptance of authority	8	B, F, P
Lack of familiarity with patient involvement or not wanting to be involved	11	
Physical or cognitive impairments	11	
GP related		
Negative attitude towards patient involvement	5	A, B, E, G, N, P
Routine behaviour in daily practice	7	A, F, N, P
Facilitators of patient involvement		
More or other resources	11	
Better prepared and informed patients	10	B
GPs using communication skills	11	

[a] A, Austria; B, Belgium; D, Denmark; E, England; F, France; G, Germany; I, Israel; N, The Netherlands; P, Portugal; S, Slovenia.

GPs' understanding of patient involvement

GPs in all countries described patient involvement as enhancing patients' understanding of different treatment options by giving explanations and information about their disease and prognosis and, after that, sharing decisions with their patients.

> *Patient involvement ... what I understand about that is that you at least inform people about what you have to offer. Secondly, that you give good information about how you handle their problem and subsequently present the possibilities again what your proposition is and check if it fits them (The Netherlands, GP 15)*

Furthermore, GPs thought of patient involvement as giving patients the opportunity to ask questions, thus facilitating patients to take responsibility and be involved.

> *I think people can be more involved if they get the opportunity to say something themselves. Not only about their medical problems but also about anything else. So a GP should make time to listen (Belgium, GP 6)*

On the other hand, GPs mentioned that the patient should take some responsibility for their involvement in the consultation and that this was itself a component of patient involvement.

> *Nowadays we have patients who have to be responsible for their health. Therefore, it's not something imposed; instead, they have to know what's going on and they always have to participate in the decision, sometimes in the choice of the examinations and always in the decision of the treatment (Portugal, GP 4)*

Positive outcomes of patient involvement

In all countries improvement of patients' acceptance of advice and adherence to medication was seen to be the most important expected positive outcome of patient involvement, along with improvements of doctor–patient relationships.

> *I would hope patients are more likely to comply if they have the information and have an understanding and some stake in the management (England, GP 13)*

Almost all GPs thought, for example, that patient involvement would improve patient satisfaction, either by reducing patients' worries or increasing their understanding of disease and treatment options.

> *Many patients are much more satisfied if they can talk to the doctor because then also different types of fear or patients' viewpoints find expression (Slovenia, GP 02)*

On the other hand, GPs thought that their own satisfaction would improve as well. They saw patient involvement as a continuing challenge and thought it would give them more background information about patients, which would enable them to judge patients' needs and preferences better.

> *You are actually going to enjoy your practice more because the patients will understand your problems and you will understand their problems better (England, GP 7)*

Finally, GPs mentioned a more equitable division of responsibilities during consultations as a result of involving patients.

> *People get a better control with their diabetes, probably a better regulation when they are involved. And if people themselves are in control of when they have to go to their yearly check-up and know what is going on at the check-ups, then we are two to remember what is going to happen (Denmark, GP 13)*

Negative outcomes of patient involvement

Some GPs were anxious about patient involvement, for example, because consultations might become longer or people would ask (in the GPs' eyes) irrelevant questions.

> *I just don't want to educate my people in this sense. Then they start asking about all they have learned in the last TV show ['Consultation' by Dr. S. Stutz] (Switzerland, GP 10)*

Perceived barriers to implementation of patient involvement

Barriers to the implementation of patient involvement were mentioned at different levels. With regard to organisational aspects of practice, GPs commonly said they had insufficient time to involve patients. Also, lack of resources, such as money or personnel were mentioned as barriers. GPs identified barriers relating to patients, such as cognitive and physical impairments. Also, acceptance of authority by older patients and their lack of familiarity with involvement or not wanting to be involved were labelled as barriers.

> *There are many who prefer being dominated by a doctor. Well, the younger patients accept my approach, but the older ones rather prefer instructions on what to do, with the general attitude: you are the doctor, you must know what I have to do (Austria, GP 14)*

> *You have to stimulate older people more. By nature they are inclined not to ask too much, to agree with what the doctor says. They didn't learn well to be interactive (Netherlands, GP 13)*

Finally, besides their daily routine in the guidance of consultations, some GPs acknowledged their own attitude towards patient involvement as barriers.

> *[Encourage older patients] to speak about issues they did not raise before, I don't like it. It seems a little inquisitive to me (...) Organise meetings ... I don't think so. It sounds like wishful thinking (France, GP 3)*

Perceived facilitators to implementation of patient involvement

GPs mentioned facilitators at different levels. As far as organisational aspects were concerned, more time, fewer patients per practice and more money would facilitate patient involvement.

> *In broad terms I would like to see patient involvement extend to political action as well. There needs to be more investment in primary care and the patients can play a part in that at the moment. Nobody is going to listen unless the patients say we think this is a good idea too (England, GP 9)*

An occasional home visit by GPs was mentioned as a facilitator. At the individual level, informed and better prepared patients who are able to take responsibility, and GPs using specific communication skills would facilitate patient involvement in consultations.

> *Today people want to be better informed. Internet has such advantages, information can be retrieved and read without hurry. This may support and enhance the consultation process...and just by this bringing more impact to the consultation (Switzerland, GP 4)*

> *Some have little sheets of paper. They write down "this and that one came to my mind" and then we go through it bit by bit (Germany, GP 8)*

International variation

GPs in different countries had more or less consistent views on patient involvement (Table 2). They all saw advantages to patient involvement, although not always in the same area. The identification of barriers, especially GP related barriers, was somewhat different. In Denmark, France, Israel, Slovenia, Switzerland, some GPs mentioned their own negative attitude towards patient involvement as a barrier.

> *We probably are some pig headed fellows from time to time, and we think things can only be done the way we already are doing them (Denmark, GP 6)*

GPs in all countries, except Austria, France, The Netherlands and Portugal, mentioned their own routine behaviour in daily practice as a barrier.

> *I had training in communication methods and I try to use the skills, but it is difficult in everyday practice. I have got difficulties by myself to put it into practice (Germany, GP 22)*

With regard to the facilitators of patient involvement, no major differences between countries emerged.

Discussion and conclusion

The most important findings from our study are the different barriers GPs perceive when enhancing involvement of older patients, their limited concept of patient involvement, their positive expectations of the outcomes of involvement of older patients and the limited variation between countries in the barriers and facilitators to the implementation of patient involvement.

Discussion

Firstly, the barriers to enhancing involvement of older patients are partly due to older patients themselves and partly to the organisation of primary care. The general prejudice of older people having difficulties becoming involved are confirmed by the GPs in our study. To judge whether this view is valid, it is crucial to know older patients' opinions about involvement, therefore, we interviewed patients of 70 years and older in another phase of the IMPROVE study, preliminary results show that patients think of involvement as an easy to access personal GP, whom they trust and who will adapt the consultation towards them as a patient (s)he knows. A review on patient preferences showed that older patients place greater emphasis on doctors making

decisions and valued a more dominant doctor to a greater extent than younger patients[18]. Whether the views of the GPs makes them interact differently in consultations with older patients and, therefore, makes it more difficult for them to involve older patients, remains unclear. There are suggestions that they may do so, for example, in a study of patient–physician interactions for those 65 years or older, there was more chatting and less structuring, resulting in less counselling, health education and prevention[16]. Whether the organisation of practice, including lack of time and resources as well as the daily routine of GPs are genuine barriers that are hard to change, or whether they served as excuses for other barriers, such as reluctance to surrender some control did not become clear.

Secondly, when GPs were asked about their concept of patient involvement, they mainly referred to communication processes in the consultation, while methods to involve patients outside consultations were not mentioned. An explanation for this might be GPs' unfamiliarity with the methods to involve patients before or after consultations. These findings suggest that the broad concept of patient involvement, which is used in the scientific literature, is only understood in a relatively superficial way by GPs in Europe.

Thirdly, the positive outcomes GPs expect from involving patients, such as improvement of adherence to medication and advice, are supported by findings in other empirical studies[8;9;17]. The fear of some GPs that consultations might become endless, may decrease when consultations are well structured and when practical tools are supplied which encourage older patients to take a more active role.

Finally, although it might be expected that barriers were influenced by the organisation of health systems or cultural factors, our comparison of barriers to implementation of patient involvement in 11 countries did not reveal clear differences between countries. The variation within countries was larger than the variation across countries. Possible explanations for this variation may be differences in socio-economic class, in cultural aspects and in spoken language between GPs and patients in some areas. This is confirmed by a recent literature review that shows that patient characteristics are an important determinant of preferences regarding primary care[18]. In addition, there may be differences in task profiles of GPs between urban and rural locations[19], different attitudes of GPs towards different problems of patients[20] and individual GP consultation style[21].

The main limitation of this study is related to the interpretation of the multi-lingual qualitative material. By using specific instructions, repeated checks of researchers in each country and a structured approach to analysis, we tried

to reduce the influence of those problems as much as possible. Nevertheless, the international nature of this study precluded an in-depth analysis. The sample of GPs was purposefully sought amongst GPs of different gender, age and urbanisation level in order to explore a broad range of ideas. This international qualitative study was performed to gain an overview of the most important factors among GPs when considering involvement of older patients and should, therefore, be seen as exploratory. The results should not be generalised in a quantitative way.

Practice implications

Our study suggests GPs are positive about involving older patients, but there are many practical problems to overcome before this ideal becomes reality. Furthermore, older patients need to be encouraged or at least informed about the possibilities for involvement during primary care consultations[22]. Implementation of involvement in daily practice needs a complete programme including an overview of the concept of patient involvement for GPs and, for example, a resource with the different methods and available instruments, as well as investment in more personnel or longer consultations. The range of activities to increase involvement may be similar in all countries, but should be adapted at the local level and modified to suit individual needs. It is crucial in particular not to demand extra services or time of GPs.

Finally, at present it is not realistic to expect high levels of involvement for every older patient at every consultation, but with a little support for the suggested implementation programme it may be possible for GPs to facilitate the involvement of their older patients more often.

References

1 Population ageing 2002. In: Proceedings of the Second World Assembly on Ageing. United Nations, Population Division, Department of Economic and Social Affairs; 2002.

2 Buetow S. The scope for the involvement of patients in their consultations with health professionals rights: responsibilities and preferences of patients. J Med Ethics 1998; 24:243–7.

3 Coulter A. Paternalism or partnership? BMJ 1999; 319: 719–20.

4 Foster J, Dale J, Jessopp L. A qualitative study of older people's views of out-of-hours services. Br J Gen Pract 2001; 51:719–23.

5 Breemhaar B, Visser AP, Kleijnen JG. Perceptions and behaviour among elderly hospital patients: description and explanation of age differences in satisfaction, knowledge, emotions and behaviour. Soc Sci Med 1990; 31:1377–85.

6 Rost K, Frankel R. The introduction of the older patient's problems in the medical visit. J Aging Health 1993; 5:387–401.

7 Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style: results from the Medical Outcomes Study. Med Care 1995; 33:1176–87.

8 Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998; 36:1138–61.

9 Rodin J. Ageing and health: effects of the sense of control. Science 1986; 233:1271–6.

10 Ogden J, Ambrose L, Khadra A, Manthri S, Symons L, Vass A, et al. A questionnaire study of GPs' and patients' beliefs about the different components of patient centredness. Patient Educ Couns 2002; 47:223–7.

11 Wensing M, Grol R. What can patients do to improve health care? Health Expect 1998; 1:37–49.

12 Tennstedt SL. Empowering older patients to communicate more effectively in the medical encounter. Clin Geriatr Med 2000; 16:61–70, ix.

13 Wensing M, Grol R. Patients' views on health care. Dis Manage Health Outcomes 2000; 7:117–25.

14 IMPROVE. http://oase.uci.kun.nl/~improve.

15 ATLAS.ti The knowledge workbench, version win 4.2 2002. Scientific Software Development, Berlin.

16 Callahan EJ, Bertakis KD, Azari R, Robbins JA, Helms LJ, Chang DW. The influence of patient age on primary care resident physician–patient interaction. J Am Geriatr Soc 2000; 48:30–5.

17 Blenkiron P. The elderly and their medication: understanding and compliance in a family practice. Postgrad Med J 1996; 72:671–6.

18 Jung HP, Baerveldt C, Olesen F, Grol R, Wensing M. Patient characteristics as predictors of primary health care preferences: a systematic literature analysis, Health Expect 2003; 6:160-81.

19 Boerma WGW, Groenewegen PP, Van der Zee J. General practice in urban and rural Europe: the range of curative services. Soc Sci Med 1998; 47:445–53.

20 Morris CJ, Cantrill JA, Weiss MC. GPs' attitudes to minor ailments. Fam Pract 2001; 18:581–5.

21 Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE. Characteristics of physicians with participatory decision-making styles. Ann Int Med 1996; 124:497–504.
22 Cegala DJ, Post DM, McClure L. The effects of patient communication skills training on the discourse of older patients during a primary care interview. J Am Geriatr Soc 2001; 49:1505–11.

Older patients' and GPs' views on different methods for improving patient involvement: an international interview study

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4

Abstract

Background

Older patients' interaction with the GP may be improved through patient involvement techniques, and there is a variety of such techniques which improve patients' involvement in their own care, although little is known about their acceptability.

Objectives

The aim of this study was to identify barriers and facilitators to using patient information leaflets and patient satisfaction questionnaires as methods for increasing older patients' involvement in general practice care by comparing their views with GPs' views on these two types of methods.

Methods

In seven countries (Austria, Denmark, Germany, The Netherlands, Portugal, Slovenia and Switzerland) 146 GPs and 284 patients aged 70 and over were interviewed about the use and the acceptability of these two methods. Interviewers followed a semi-structured interview guide, and all interviews were tape-recorded and transcribed verbatim.

Results

The arguments for using patient satisfaction questionnaires were that they would provide the GP with more information, function as a basis for change, increase patients' self confidence and make them more conscious of what to expect. Barriers for their use were cognitive impairment among patients, fear that they would not answer honestly and opposition to written material. The arguments for patient information leaflets were that they could support patients' memories, educate patients and promote their self-responsibility. The barriers were cognitive impairment among patients and fear that they would give them false impressions of what to expect.

Discussion

Both instruments were generally well accepted by both GPs and patients. Their use seemed to be dependent upon the individual GP's attitude and the patients' cognitive capacities.

Introduction

Involvement in the decision-making and planning of their own general practice care is actively demanded by some patients, and it is one of the GP's responsibilities towards his/her patients[1]; it is an ethical principle and, in some countries, even a legal requirement[2–4]. Recognition of the need for patient involvement is rooted in indications that patients often find information from the GPs to be insufficient and inadequate[5], often do not voice their true agendas in the consultation[6] and seek additional information elsewhere[5]. Lack of patient involvement may also cause some dissatisfaction and lead to poor treatment compliance.

Patient involvement takes many forms and has been variously described in terms like patient empowerment, doctor–patient partnership and shared decision making. These strategies aim to improve the quality and effectiveness of consultations[7]. To overcome the theoretical limitations of these different forms of patient involvement, we use the global term 'patient involvement' which refers to activities aimed at 'enabling patients to take an active role in deciding about and planning their care'. Procedures involving patients may be implemented on a national, a regional or a practice level and can be applied within an episode of care and in relation to each consultation. Examples of methods involving patients include: (a) Written materials, e.g. information leaflets about clinical conditions or questionnaires seeking patients' views on their care or symptoms; and (b) Interactive communication skills, e.g. those used by the doctor in consultations with patients, or the use of a third person (relative, informal carer, nurse, etc.) to help patients express their preferences. However, the ability of these different methods to actually increase patient involvement remains sparse.

This paper aims to discuss methods for improving involvement in the practice setting and in the single consultation. We will attempt to identify barriers and facilitators for using patient information leaflets and patient satisfaction questionnaires as instruments for increasing older patients' involvement in general practice care by comparing their views with GPs' views on these two types of methods.

The study will also explore whether country-specific differences can be identified. Patients aged 70 years and over were selected because they have many diseases and chronic conditions, the treatment of which requires greater patient involvement. Moreover, the elderly require special attention as they may also find it difficult to adequately describe their symptoms[8] and conceptually engage with the GP. Finally, they are often less demanding

and more accepting of authorities than younger patients. Our study was conducted within the framework of the international IMPROVE study[9] set up to investigate barriers and facilitators for increasing the involvement of older patients aged 70 years and over in their general practice care. The presented findings are based on data from seven of the eleven participating countries.

Methods

As part of the international IMPROVE study data were collected from eleven countries, but due to technical problems only data from seven countries were analysed in this study.

Instruments

We investigated one instrument primarily used for involvement at practice level and one primarily for involvement within an episode of care. As representative of the former, a Patient Satisfaction Questionnaire, the EUROPEP instrument, was chosen. This instrument is fairly new, validated translated versions are available in all the participating countries and it is being widely used in several countries[10;11]. To represent the latter, Patient Information Leaflets were chosen because they are widely used in almost every practice either passively (i.e. they are available in the waiting room) or actively (i.e. the GP hands them out to the patient advising the patient to study the leaflet). No uniform translated version of a patient information leaflet was available and the leaflets used therefore differed from country to country. However, each leaflet was typically a small booklet informing about a specific disease, e.g. diabetes or hypertension.

Participants

Within the framework of the international IMPROVE study, a purposeful stratified sample[12;13] of 233 GPs and 360 patients aged 70 and over from 11 countries (Austria, Belgium, Denmark, England, France, Germany, Israel, The Netherlands, Portugal, Slovenia and Switzerland) were interviewed about their attitudes towards and experiences with patient involvement and use of the ways of obtaining patient involvement described above. The GPs were stratified according to sex, age (cut-off: 45 years old) and practice setting (city, urbanised, rural). Patients were stratified according to sex, age (70–79 years and 80+ years) and health status (isolated illness, chronic illness, life threatening illness, non-attenders). A sample of two GPs in each of the 12 stratifying cells

and two patients in each of the 16 cells was chosen from each country. We also sought to select patients from the three different settings (city, urbanised, rural).

Interviews

Interviews were conducted using a semi-structured interview guide with a combination of pre-structured and open-ended questions[14] developed by the co-ordinating research centre in England and adapted in collaboration with the researchers from all 11 participating countries. The main interview themes were barriers and facilitators to patient involvement in general practice care. Before the interviews, the GPs received project information detailing, among others, our definition of patient involvement and the two instruments of patient involvement: a national, validated version of the EUROPEP patient satisfaction questionnaire and a patient information leaflet. The patients did not receive these tools before the interviews, but they were presented to them during the interviews. GPs and patients were then asked to describe their experiences with and attitudes towards these types of tools, and what they thought were advantages and disadvantages. The interviews were performed either by the researchers themselves or by trained interviewers from August 2000 until April 2001. All interviews were tape recorded, transcribed verbatim and then entered into the data analysis programmes Atlas.ti or QSR Nudist.

Data analysis

All countries conducted the study, but it was not possible for researchers from all countries to access their data files to retrieve the information needed for the joint analysis. The present results are therefore based on data from seven countries: Austria, Denmark, Germany, The Netherlands, Portugal, Slovenia and Switzerland; and they include 146 GPs and 284 patients as illustrated in Tables 1 and 2. Based on a contents analysis of interviews from four countries (Belgium, Germany, The Netherlands, and Slovenia), a common code list was devised through consensus discussions at a workshop between researchers from six participating countries (Belgium, Denmark, France, Germany, The Netherlands, Slovenia). The GP and patient code-lists paralleled each other, each containing 37 codes categorising GPs' and patients' ideas about patient involvement, like facilitators, barriers, perceptions and opinions of the various methods for patient involvement presented to them. In each participating country, all interviews were then systematically scrutinised for the presence of quotations illustrating these codes. To ensure country-consistent coding, two researchers in each country coded at least the same five GP interviews and

the same five patient interviews independently. At the international level, an interview with a German and a Dutch GP and a German and a Dutch patient were translated into English. Afterwards they were coded independently by a researcher from each country and then compared with the original coding. Finally, a researcher from each country coded an English GP and an English patient interview and then the English co-ordinating team compared the coding results. No important or systematic coding differences were found. Researchers were subsequently asked to return to the original documents and to identify all the coding results and quotations made on the patient information leaflet and the patient satisfaction questionnaire and subdivide those codes into smaller meaning units presenting arguments for and against these instruments. The new sub-codes, all illustrated with a typical quotation translated into English, were then sent to the two first authors (TAG and RW) who compared the new codes, traced country specific characteristics and then merged the new codes into inclusive categories representing all countries.

Results

The stratification criteria outlined in the sample for both GPs and patients were met in the total sample. A total of 146 GPs were interviewed: 53% were male, their mean age was 47 years (range: 31–81) with 45% under 45 years of age. 41% of GPs came from city practices, 27% from urban practices and 32% from rural practices (Table 1). Among the 284 interviewed patients, 43% were male and their mean age was 79 years (range: 70–96) with 56% between 70 and 80 years of age (Table 2).

Table 1 Demographic characteristics of interviewed GPs (absolute numbers)

Country	Age		Gender		Practice			Total
	<45	≥45	Male	Female	City	Urban	Rural	
Austria	7	13	11	9	9	5	6	20
Denmark	6	6	5	7	4	4	4	12
Germany	11	14	15	10	10	6	9	25
Netherlands	10	10	11	9	7	6	7	20
Portugal	12	11	9	14	10	8	5	23
Slovenia	13	13	12	14	11	7	8	26
Switzerland	6	14	14	6	9	3	8	20
Total	65	81	77	69	60	39	47	146

Table 2 Demographic characteristics of interviewed patients (absolute numbers)

Country	Age		Gender		Region			Health status				Total
	70-80	80+	M	F	City	Urban	Rural	Is[a]	Ch[b]	LT[c]	NA[d]	
Austria	32	18	16	34	27	6	17	1	44	4	1	50
Denmark	14	10	11	13	10	6	8	5	9	7	3	24
Germany	19	16	14	21	7	17	11	5	20	7	3	35
Netherlands	15	13	13	15	8	14	6	4	12	6	6	28
Portugal	41	38	38	41	30	20	29	22	19	17	21	79
Slovenia	22	16	19	19	-	-	-	10	11	8	9	38
Switzerland	15	15	10	20	-	-	-	8	9	8	5	30
Total	158	126	121	163	(82)	(63)	(71)	55	124	57	48	284

[a] isolated illness; [b] chronic illness; [c] life-threatening disease; [d] non-attender

Patient Satisfaction Questionnaire

An overview of the identified categories and their typical expressions is shown in Table 3 and Box 1. GPs and patients in most countries agreed that the patient satisfaction questionnaires would give the GP additional information and that the questionnaires might serve as a basis for change. In some countries, GPs thought the questionnaires would enhance patients' self-confidence and make them more conscious of what to expect. Patients found that the use of such questionnaires would promote openness, make it easier for them to express their criticisms and improve confidence between patient and GP. Some GPs and patients thought that the patient satisfaction questionnaire method would mislead the GPs because patients would be reluctant to demonstrate disloyalty and therefore would not always answer the questionnaire truthfully (Table 4 and Box 2). Both GPs and patients also thought that the questionnaire would often be too difficult for older people mainly due to cognitive or physical deficits, e.g. lack of education, sight problems, etc. Preference for oral conversation over written material was mentioned both by GPs and patients as another argument against the satisfaction questionnaires as a method for improving patients' involvement. In addition, some GPs were afraid that questionnaires would augment organisational work, be time consuming and give patients unrealistic expectations that the GP would be unable to meet.

Apart from the arguments against the use of patient satisfaction questionnaires in general, both GPs and patients had objections concerning the design of the instrument, e.g. its length and readability.

Table 3 Advantages of patient satisfaction questionnaires (the numbers refer to the corresponding citations in Box 1)

	GPs	Patients
Feedback information and basis for change [A,DK,G,NL,P,SL,SW]	✓1	✓2
Easier for patients to utter criticism/promote openness [A,DK,G,NL,P,SW]	✓3	✓4
Positive attitude in general [A,G,SL,SW]	✓5	✓6
Increase patients' self-confidence [NL,P,SW]	✓7	
Make patients more conscious of what to expect [NL,P]	✓8	
Improve confidence between patient and GP [DK,SL]		✓9
Instrument characteristics (e.g. readability, layout etc) [G]		✓10

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

Box 1 Citations illustrating the themes in Table 3

1 Well, but you do get a lot of good information about it. In that way you may get a chance to influence e.g. the telephone hours. Perhaps the telephone hours are too short—or the telephone hours should be organised differently. They must go to the secretary instead of directly to the GP when they come in. And also some other things. It might be very good to find out from a questionnaire like this what the patients actually think. [DK 13]

2 Well, I think it's kind of useful for a patient and for a GP to see the patient's view of the matter, and it's also good for a GP to get feedback. I don't have any negative opinions. [SL 6]

3 It is important that patients have them and make their evaluations on how the service works in this way. It is very important they give their opinion. [P 11]

4 Because I think that most of the patients don't dare to contradict the GP. If they have a questionnaire, they can write it down, which is easier. [A 43]

5 For sure it [the questionnaire] is quite interesting. I would regard it as positive. [G 12]

6 Well, if I read it properly, I would probably agree with everything and would only express a positive opinion. Because in my entire lifetime—and I'm 71 years old—I haven't had any troubles with a doctor. And I like it: like him, like me. [SL 2]

7 The patient can see that his opinion is important, that he can contribute something and is taken seriously. [SW 1]

8 A good thing is that people might get more conscious themselves about what they may expect. [NL]

9 It could give you a kind of a line of approach to greater confidence through such things, right? It would give you greater confidence in the GP? Yes, I would think so. [DK 1]

10 The questions are posed in a way, which is understandable to everyone.

Table 4 Barriers to using patient satisfaction questionnaires (the numbers refer to corresponding citations in Box 2)

	GPs	Patients
Misleading/not a true picture (patients afraid to show disloyalty) [A,DK,D,NL,P,SL,SW]	✓1	✓2
Too difficult for older people (cognitive and/or physical deficits) [A,DK,G,NL,P,SL,SW]	✓3	✓4
Useless—doubtful effect/people are not interested [A,DK,G,NL,SL,SW]	✓5	✓6
Prefer oral conversation [A,SL,SW]	✓7	✓8
More organisational work/time consuming [A,G,NL,P]	✓9	
Give patients unrealistic expectations [DK,NL]	✓10	
Instrument characteristics (e.g. too long, too difficult) [A,DK,G,NL,P,SL,SW]		✓11

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

Box 2 Citations illustrating the themes in Table 4

1 I am afraid that the patient will often be too nice to the GP. And, on the other hand, it is also important for the GP to get personal feedback from the patient. That is, you can say incredibly much that can be misunderstood. [DK 15]

2 . . . if you imagine that it is someone who must go back to the GP, right? Then it might—some of the answers will perhaps not be well received by the GP. Therefore you might have second thoughts about being quite honest when you answer it. [DK 3]

3 I have not seen someone of 75 years complete such a list easily; I think it is very difficult for them. [NL]

4 Perhaps it's really too difficult for some people who are less acquainted with all these things. [SL 19]

It is not easy for someone who cannot read or write. Many cannot see well either. You know when your eyes start to get tired, there is nothing you can do, and many cannot see well. [P 1]

5 I haven't seen anything useful with this questionnaire. I don't see what benefit the patients can get from it. It is only worth something for the person carrying out the research. The patients don't get any benefit from it. [SL 5]

6 It isn't bad, is it? But most patients aren't interested. They are satisfied to get their pills and leave. [G 24]

7 I would prefer to talk to them because that is more useful. [A 14]

8 I still believe that a conversation is better than filling out a questionnaire [A 8]

9 The organisational expenses are simply too big. [G 8]

The questionnaire takes lots of time and work. [P 22]

10 The problem is that you get some expectations that are higher than the GP can meet. [DK 10]

11 This [type size] is too small, and it needs a line otherwise it will not work. If you would like to focus on older people, then, yes, a lot bigger. [NL]

Patient Information Leaflet

The identified categories and typical expressions pertaining to the leaflets appear in Table 5 and Box 3.

GPs and patients in all countries agreed that patient information leaflets were excellent means of supporting patients' memories, of educating patients and thus of supporting and promoting their self-responsibility. GPs also mentioned that use of information leaflets saves time, increases compliance, promotes patient involvement and paves the way for involving a third person such as a carer or a relative. Patients further mentioned having written materials could save them a visit to the GP and reduce their worries because they would know more about their condition.

Arguments voiced against the leaflet (Table 6 and Box 4) were that it was too difficult to use for older people because of their cognitive and/or physical deficits, e.g. poor eyesight, and that it could make patients more anxious and represent a possible source of misunderstanding, e.g. if the patient did not understand the contents of the leaflet or if the contents was at variance with the GP's opinion or recommendations. Other arguments against the leaflet from both GPs and patients were that it was too general and not focused on the individual patient. One GP added that it could also serve as an excuse to the GPs who would just hand out the leaflet to the patient without giving him/her adequate information. Some GPs and patients found the leaflets to be unhelpful either because they thought they would not be accepted by the patients or the GPs or because they preferred oral conversation. Again extra work was mentioned by some GPs as a barrier and, finally, both GPs and patients acknowledged that the design of the leaflet, including its layout and sponsorship, could prevent it from being an easy and honest source of information and patient involvement.

Country-specific themes

Not all themes were found in all participating countries, but no systematic differences between countries could be identified.

Table 5 Advantages of using patient information leaflets (the numbers refer to the corresponding citations in Box 3)

	GPs	Patients
Support memory [A,DK,G,NL,P,SL,SW]	✓1	✓2
Educate patients and support self-responsibility [A,DK,G,NL,P,SL]	✓3	✓4
Promote involvement/involve third parties or relatives [DK,NL,P,SL]	✓5	✓6
Instrument characteristics [A,DK,G,NL,P,SL,SW]	✓7	✓8
Save time [A,G,SL,SW]	✓9	
Increase compliance [P,SL]	✓10	
Save a visit to the GP [DK,G,SL]		✓11
Reduce worries [DK]		✓12

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

Box 3 Citations illustrating the themes in Table 5

1 That they take it again and again and maybe sometimes it would be successful . . . or when forgotten they can look it up themselves. [A 18]
2 It informs clearly and concisely about a subject and you read it again whenever you have forgotten something. [NL]
3 . . . as I say, it is a chronic disease, they get diagnosed and that means it is something they have to live with for the rest of their lives. And it is something they have to get involved in and take responsibility for. Otherwise you cannot have diabetes. That's why I think it can be good to give them a bit of material to bring home, and then come back so they have a little more knowledge about it the next time we are going to talk about it. Then they get a little more information that way. [DK 3]
4 It is useful because you can read it yourself and see, for instance, what high blood pressure means to your health, you read about organ damages and so on. Then you can take measures yourself or change your way of life. You live a healthier life. You eat healthier food, you move more and so on. [SL 12]
5 I also give a leaflet to relatives. If there is something a patient doesn't notice, the relatives can notice it. And then the relatives participate. They can help. They do it together. [SL]
6 So that we get in touch with the GP and tell her that we need this or that. [P 21]
7 When the leaflets have drawings—and some of them have—they are good and we use them. [P 31]
8 If there are no foreign words in it, everything is told in German, it is all right. It could be expanded. [G 23]
9 If it is an information leaflet, then it actually helps saving time. [G 22]
10 Let's say with a certain disease, when a disease gets worse. If you give a patient a leaflet about it, for instance proper blood pressure regulation, then this advice will bear more fruit. [SL 1]
11 I think it might be good. You could see what—and perhaps save a visit to the GP as well. If you could find out by yourself. Now I haven't read it, so I really don't know what it contains. [DK 17]
12 Yes, it might be good. You might feel more safe by getting to know a little about what it is about. [DK 7]

Table 6 Barriers to using patient information leaflets (the numbers refer to the corresponding citations in Box 4)

	GPs	Patients
Too difficult for elderly people (cognitive and/or physical deficits) [A,DK,G,NL,P,SL,SW]	✓1	✓2
Make patients more anxious/basis for misunderstanding [A,DK,G,NL,P,SL,SW]	✓3	✓4
Too general/too simple/not focused on the individual patient [A,NL,P,SL,SW]	✓5	✓6
Useless/not accepted by patients or GPs [A,DK,G,NL,SW]	✓7	✓8
Instrument characteristics [A,DK,G,P,SW]	✓9	✓10
Pretext to the GPs [DK]	✓11	
More organisational work [A,G,NL,SW]	✓12	
Too many different leaflets [NL]		✓13

A = Austria; DK = Denmark; G = Germany; NL = The Netherlands; P = Portugal; SL = Slovenia; SW = Switzerland.

Box 4 Citations illustrating the themes in Table 6

1 I think it is quite complicated for older people. Most of my patients won't be able to handle it. [G 6]
2 There are many who don't read it properly. That, about reading and understanding the meaning, that is probably a problem for many older people. [DK 18]
Older people cannot understand even if they can read. [P 8]
3 Disadvantages may be that sometimes a patient reads a certain thing and misunderstands it. If he doesn't have a possibility of talking with somebody, he can understand it in a wrong way and interpret a certain sentence in a wrong way. [SL 2]
There are only few patient leaflets that don't arouse fear. [SW 14]
4 If you know too much, it's even worse. If I read something now, if something is written about a disease, I might think: I have exactly this [disease]. You see, and I would torment myself, I would feel anxious again. [SL 3]
5 Sometimes the story that's in there does not fit the patient at all. It is a good global leaflet, but it is not focused on the individual patient. [NL]
6 It isn't individual. It is general but every patient has his/her own nature. [A 1]
7 There are many patients who are not interested in getting a leaflet every time. [G 22]
8 Interviewer: Do you think it might be useful to get such a thing to take home with you, e.g. if you got diabetes II or some other disease? Interviewee: I don't know. Because I get—then we get told by the GP. I count on. Because when we get tablets and things like that—start at something,— they inform us all right. [DK 9]
9 Also, very often they don't have complete information as we wish, or else they have too much information and it is discouraging for the patient to be forced to read. [P 11]
10 It isn't individual, it is general, but every patient has his/her own nature. [A 1]
11 . . . to the GP it can become a pretext. You think you have given them something to bring home, but they have just brought it home and they haven't read it. Then you think you have informed them about something. [DK 3]
12 Maybe it's a disadvantage that there are too many papers. I have a lot of information leaflets; my tables are full of them. [A 8]
13 There are shelves full of leaflets. Then you think what on earth should I take with me? A bit too many. [NL]

Discussion

The results of this qualitative study pointed to both some positive and negative aspects of patient information leaflets and patient satisfaction questionnaires which may have implications for their use in daily clinical practice.

The patient information leaflets were widely accepted and used among GPs as well as patients. Positive aspects were that patient information leaflets can support patients' memories; educate patients, support their self-responsibility; promote involvement; increase compliance and save time, which is consistent with what has been found elsewhere[5]. Further, it has been shown that patient information leaflets increase patient satisfaction and perception of communication[15]. Despite discussions on whether the purpose of patient information leaflets is to educate or to empower patients[16], it seems beyond questioning that use of patient information leaflets is a good idea and a helpful tool to patients as well as to GPs when used with care. One of the major barriers to using patient information leaflets may be the difficulty in finding non-commercial leaflets of high quality tailored to the individual patient. Our study findings show that leaflets should always be accompanied by careful oral instruction and/or information to the patients about the content and use of the leaflets. This may influence the timesaving aspect in the short run, but in the long run the leaflet may still save the patient one or more visits to the GP providing it is a good leaflet with relevant, easy to understand information and instructions.

It appears that both GPs and patients see some advantages and benefits of using patient satisfaction questionnaires. Studies that have used patient satisfaction questionnaires one way or another practically all report response rates of 70% or higher[17–21] which indicates that a majority of patients are willing to spend time using the instrument. However it has been shown that acceptance and responses to patient satisfaction questionnaires are associated with variations in patient characteristics, i.e. increased age and increased proportion of male patients are associated with lower satisfaction scores[21]. Concerning the acceptability among GPs, a randomised study showed that GPs who had used a patient satisfaction questionnaire saw more barriers and found it less relevant to their practice than a group of control GPs, who had not used the tool[22].

The barriers found in our study clearly address some points that should be taken into consideration when designing and using patient information leaflets as well as patient satisfaction questionnaires with older patients. It is important that these tools are written in large font type, easy to understand

yet not too simple and, perhaps most important, that the handing over to the patient is followed by clear and understandable oral information on its purpose and its use.

Comparisons of GPs' and patients' views on patient information leaflets and the patient satisfaction questionnaire revealed no conflicting findings. The within-group variation seemed to exceed the between-group variation, but it should be noted that in another part of the IMPROVE study we found that GPs and patients did seem to differ in their global conceptions of patient involvement. GPs' perception of patient involvement tended to be very much in line with our definition, i.e. as a question of assigning a more active role to the patients[23], while patients were more likely to perceive patient involvement as a 'caring relationship' (Bastiaens H, Van Royen P, Pavlic DR, et al. unpublished work). No obvious or systematic differences were observed between countries in terms of opinions about patient information leaflets and patient satisfaction questionnaires, but this lack of data is not tantamount to claiming that such differences do not exist. The qualitative design of this study was not optimal for documenting significant differences between countries, which may be better explored by means of quantitative methods.

A large, international qualitative study like the present has several weaknesses which should be considered. The most important are probably the language barrier, the distance between researchers and the difficulties in using uniform procedures for gathering, processing and analysing data. As described in the method section, care was taken to ensure consistency in sampling, interviewing and data analysis. This and the large number of GPs and patients from different countries participating in the study strengthen the reliability of the findings. We therefore have reason to believe that this study reflects GPs' and older patients' views on the selected methods for patient involvement. However it should be stressed that a qualitative study like this ought to be followed by a larger quantitative study to assess the general feasibility; acceptability and effect of the patient involvement approach on patient outcome and provider and patient satisfaction.

Conclusion

The diversity of opinions about and preferences for the studied patient involvement methods draws a rather nuanced and complex picture of patient involvement and also reflects and underscores the point that patient involvement achieved by these methods may not be within the reach of all patients and perhaps not all GPs. Some patients are not capable of being involved and others do not want to be involved, and likewise some GPs

were much in favour of using these methods, while others had various reservations. The main barriers to using these types of instruments may be the lack of instruments tailored to meet the needs of the elderly and the individual GP's attitude. This should be considered in dealing with GP education. This study confirms that a conscious and goal-oriented use of these approaches on selected patients and perhaps selected conditions may be one way of improving involvement in European general practice, but we need further studies to assess the general feasibility and effect of this approach to raise patient involvement.

References

1 Buetow S. The scope for the involvement of patients in their consultations with health professionals: rights, responsibilities and preferences of patients. J Med Ethics 1998; 24:243–7.

2 Coulter A, Elwyn G. What do patients want from high-quality general practice and how do we involve them in improvement? Br J Gen Pract 2002; 52:S22–6.

3 Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract 1999; 49:477–82.

4 Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, et al. Systematic review of involving patients in the planning and development of health care. BMJ 2002; 325:1263.

5 Coulter A, Entwistle V, Gilbert D. Informing Patients. An assessment of the quality of patient information materials. London: King's Fund; 1998.

6 Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. BMJ 2000; 320: 1246–50.

7 Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. Eur J Gen Pract 2003; 9:62–5.

8 Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. Br J Gen Pract 1997; 47:427–30.

9 IMPROVE study. http://oase.uci.kun.nl/~improve/

10 Grol R, Wensing M. Patients evaluate general/family practice: the EUROPEP instrument. Nijmegen: Centre for Quality of Care Research, 2000.

11 EUROPEP instrument. http://www.equip.ch/groups/europep.html

12 Miles MB, Huberman AM. Qualitative data analysis — An expanded sourcebook. Thousand Oaks: SAGE Publications; 1994.

13 Sandelowski M. Sample size in qualitative research. Res Nurs Health 1995; 18: 179–83.

14 Britten N. Qualitative Research: Qualitative interviews in medical research. BMJ 1995; 311:251–3.

15 Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J, et al. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ 2004; 328:441.

16 Dixon-Woods M. Writing wrongs? An analysis of published discourses about the use of patient information leaflets. Soc Sci Med 2001; 52:1417–32.

17 Zebiene E, Razgauskas E, Basys V, Baubiniene A, Gurevicius R, Padaiga Z, et al. Meeting patient's expectations in primary care consultations in Lithuania. Int J Qual Health Care 2004; 16:83–9.

18 Wensing M, Vedsted P, Kersnik J, Peersman W, Klingenberg A, Hearnshaw H, et al. Patient satisfaction with availability of general practice: an international comparison. Int J Qual Health Care 2002; 14:111–8.

19 Meakin R, Weinman J. The 'Medical Interview Satisfaction Scale' (MISS-21) adapted for British general practice. Fam Pract 2002; 19:257–63.

20 Kersnik J, Svab I, Vegnuti M. Frequent attenders in general practice: quality of life, patient satisfaction, use of medical services and GP characteristics. Scand J Prim Health Care 2001; 19:174–7.

21 Baker R. Characteristics of practices, general practitioners and patients related to levels of patients' satisfaction with consultations. Br J Gen Pract 1996; 46: 601–5.
22 Wensing M, Vingerhoets E, Grol R. Feedback based on patient evaluations: a tool for quality improvement? Patient Educ Couns 2003; 51:149–53.
23 Wetzels R, Geest T, Wensing M, Ferreira P, Grol R, Baker R. GPs' views on involvement of older patients: A European Qualitative study. Patient Educ Couns 2004; 53:183–8.

Self-management is not related to reduced demand in primary care in independent living elderly

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5

Abstract

Objectives

To determine what effect self-management orientations and perceptions of health problems had on older adults' frequency to seek medical advice.

Design

Population based prospective cohort study.

Setting

Thirty-four general practices in the Netherlands.

Participants

All patients from the practices' population aged between 70 and 80 years, living independently in the community. Those with a short term terminal disease were excluded.

Measurements

Three surveys, containing questionnaires that included age, gender, education level, composition of household, general state of health and health locus of control.

Results

The most important determining factors for older people to visit their general practitioner (GP) were pain and the belief that others, particularly the GP, have much influence on their health status. Patients with a strong self-management orientation visited their GP as often as others.

Discussion

GPs should be attentive to unreported non-painful health problems in older adults. Strong self-management in older patients does not necessarily lead to fewer contacts in primary care.

Introduction

Self-management refers to patient behaviour which keeps illness under control and minimizes its impact on health and quality of life. Optimal self-management may improve health outcomes as well as the efficiency of health care services and patient autonomy[1]. Seeking medical advice for a health problem is an important aspect of self-management and an important role of the general practitioner (GP) is to support self-management in patients. However, patients with a strong self-management orientation may not seek advice for their health problems, while those with a weak self-management orientation may seek advice for problems that do not necessarily need medical attention. In older adults both underreporting of health problems[2] and feelings of dependency on the doctor have been documented[3;4]. It remains unclear whether not seeking medical advice reflects a strong self-management orientation or other cognitions, such as denial of bodily symptoms[5;6]. Our study aimed to determine what influence self-management orientations and perceptions of health problems had in older adults on their tendency to seek medical care.

Methods

Study design

For this population based prospective cohort study we used available data from a randomised trial which is reported elsewhere[7]. The trial showed that a mailed educational package did not change attendance of the GP, so we used the total study population from this trial. The Ethical Committee of the University Medical Centre Nijmegen gave approval for the study.

Study sample

Subjects were recruited from the practice lists of 34 GPs. In the Netherlands all subjects are listed with a GP for a longer period of time. They get all the professional medical care from or through that GP. Patients were eligible for the study if they were aged between 70 and 80 years, were living at home and were not seriously ill. After the GP excluded patients who did not meet the inclusion criteria, the researchers made a random selection of 30 patients (or all patients if less were registered) from each general practice. In one general practice there were only 28 older patients who could be included. In total 1018 older adults were invited for the study. A patient who died and another who had become seriously ill during the study period were not included in the follow-up measurements.

Measures

We report on data from questionnaires completed by patients on three different moments: baseline (June 2001), at three months later and at 12 months. The baseline questionnaire included the following measures: age, gender, education level (8 categories), composition of household (6 categories), general state of health (MOS-20)[8] and the health locus of control[9]. The MOS-20, which was used to measure perceptions of health problems, had six subscales: physical functioning, physical role constraints, social functioning, mental health, health perceptions and bodily pain. Health locus of control had three subscales: an internal orientation (reflecting a strong self-management orientation); an external orientation on powerful others, particularly the physician; and external orientation on chance (both reflecting a weak self-management orientation). The follow-up measurements included patient reported number of GP visits since last questionnaire and over a total of 12 months.

Data analysis

Missing values were substituted with the individual mean scale value. Data were entered into SPSS (version 11). Responders were compared with a representative sample in the age category with respect to MOS-20 scores[10]. Linear regression analysis was used to identify determinants of attendance rates. The dependent variable was the number of consultations. Independent variables were the six MOS-20 subscales and the three subscales of health locus of control and the categorical variables: education level and composition of household. Responders were excluded from this study when their consultation rate was missing.

Results

Of 1018 invited patients, 658 responded by sending in their questionnaires. The patient consultation rate at 12 months was known in 496 responders (out of 658); on average they had visited their GP 5,5 times in this period (range 1-31). Mean age of responders was 75 years old (range 70-80 years) and 55,4% were women. Slightly more than half of all responders had a low education level, 16,7% had a high education level. Mean scores of MOS-20 are presented in Table 1. MOS-20 scores of excluded responders (because their consultation rate was missing) were similar to responders in the same age group.

Table 1 Mean scores of MOS-20 and Health Locus of Control of responders

Predictors	N	Mean score	SD	Reference group age 75-79 (n=739)
MOS-20 (Score range 0-100)				
- Physical function	475	55,3	33,0	57,8
- Role function	479	65,3	45,4	64,8
- Social function	482	78,5	26,0	72,7
- Mental health	478	73,0	19,8	73,3
- Health perception	431	63,4	23,5	63,5
- Bodily pain	474	37,4	35,0	32,9
Health Locus of Control (Score range 1-5)				
- Internal	428	2,9	0,8	
- External, powerful others	436	2,7	0,9	
- External, chance	378	3,0	1,0	

The predictors of the GP visits are presented in Table 2. Most important predictor appeared to be the perception of bodily pain. The more pain patients felt, the more frequent they had visited their GP. Furthermore, we found that the more patients felt that their doctor has much power to influence their health status, the more frequent they had visited their doctor. A strong internal or external orientation on chance did not influence attendance.

Table 2 Patients' predictors of the decision to seek advice from their GP (n=496 patients)

Patients' predictors	Standardised Coefficients Beta	t	Significance (p value)
MOS-20:			
- Physical functioning	-0,108	-1,133	0,258
- Role functioning	0,017	0,186	0,853
- Social functioning	-0,079	-0,956	0,340
- Mental health	-0,091	-1,285	0,200
- Health perception	0,069	0,759	0,449
- Bodily pain	0,196	2,551	0,011
Health Locus of Control:			
- internal	0,049	0,687	0,493
- external, powerful others	-0,146	-2,229	0,027
- external, chance	0,042	0,662	0,508
Education level	0,043	0,689	0,491
Household	-0,026	-0,442	0,659

Discussion

The most important determinants for older people to visit a GP were pain and the belief that others, particularly the doctor, have much influence on the health status. The decision to visit the GP was not related to other perceptions of health problems, such as poor mental health or role limitations. Furthermore, older adults with a strong internal health locus of control did not visit their doctor less often than others. The findings of this study confirm those of previous studies, which also showed that other factors than objective physical symptoms influenced the decision to seek medical advice[11]. Our study emphasised the importance of pain perceptions, which appeared to be dominant. This implies that older adults were less inclined to seek advice for other problems, such as hearing loss, although effective treatment or rehabilitation may be available. Our study suggests that underreporting of health problems may be particularly problematic in problems, which are not painful. Furthermore, our study suggested that a strong orientation on self-management does not necessarily lead to underreporting of health problems, as patients with a strong internal health locus of control did not visit their GP less frequently than others. On the other hand, a weak self-management orientation may imply that medical advice is sought for minor problems, because patients with an external health locus of control had visited their doctor more frequently.

As opposed to many previous studies on attendance rates, our study was based on a prospective design and included relevant patient-reported measures to explain attendance rate. The main limitations of the study were the reliance on patient–reported measures and the limited information on patient characteristics. A study showed that patients tend to report less doctor utilization than recorded in computerized provider records[12].

One clinical implication of this study is that GPs should recognize unreported non-painful health problems in older adults, particularly if effective management is possible. A second implication is that strong self-management in older patients does not necessarily lead to fewer contacts in primary care. Ideally, the GP provides effective education and counseling to support self-management in patients.

References

1 Bodenheimer T, Lorig K, Holman H, et al. Patient self-management of chronic disease in primary care. JAMA 2002; 288:2469-75.

2 Brown K, Boot D, Groom L, et al. Problems found in the over-75s by the annual health check. Br J Gen Pract 1997; 47:31-5.

3 Woodward NJ, Wallston BS. Age and health care beliefs: self-efficacy as a mediator of low desire for control. Psychol Aging 1987; 2:3-8.

4 Smith RA, Woodward NJ, Wallston BS, et al. Health care implications of desire and expectancy for control in elderly adults. J Gerontol 1988; 43:1-7.

5 Walters K, Iliffe S, Orrell M. An exploration of help-seeking behaviour in older people with unmet needs. Fam Pract 2001; 18:277-82.

6 Morgan R, Pendleton N, Claque JE, et al. Older people's perceptions about symptoms. Br J Gen Pract 1997; 47:427-30.

7 van Eijken M, Wensing M, de Konink M, et al. Health education on selfmanagement and seeking health care in older adults: a randomized trial. Patient Educ Couns 2004; 55: 48-54.

8 Stewart AL, Hays RD, Ware JE Jr. The MOS short-form general health survey. Reliability and validity in a patient population. Med Care 1988; 26:724-35.

9 Wallston KA, Wallston BS, DeVellis R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. Health Educ Monogr 1978; 6:160-70.

10 Kempen GIJM, Brilman EI, Heyink JW, et al. Het meten van de algemene gezondheidstoestand met de MOS Short-Form General Health survey (SF-20), een handleiding. Groningen: Noordelijk Centrum voor gezondheidsvraagstukken, 1995.

11 Wolters R, Wensing M, van Weel C, et al. Lower urinary tract symptoms: social influence is more important than symptoms in seeking medical care. BJU Int 2002; 90:655-61.

12 Ritter PL, Stewart AL, Kaymaz H, et al. Self-reports of health care utilization compared to provider records. J Clin Epidemiol 2001; 54:136-41.

Section 2

Exploration of methods for improving an older patient's involvement

Interventions for improving an older patient's involvement in primary care episodes: a Cochrane review

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6

Abstract

Background

Accumulating empirical studies show that patients who are encouraged to participate more actively in consultations with their doctors, have more favourable health outcomes, in terms of both physiological and functional status, than those who are not. Besides this, there is a growing expectation among patients that they should be involved.

Objectives

To identify interventions in primary medical care that improve older patients' involvement in their health care, to describe the outcome measures used to assess these interventions; and to summarise their effects.

Search strategy

We searched the Cochrane Consumers and Communication Review Group Specialised Register (May 2003); Cochrane Central Register of Controlled Trials (CENTRAL); The Cochrane Library: The Cochrane Library issue 1, 2004; EMBASE: 1988-June 2004; PsycINFO: 1872-June 2004; DARE: The Cochrane Library issue 1, 2004; ERIC: 1966-June 2004; CINAHL: 1982-June 2004; Sociological Abstracts: 1963-June 2004; Dissertation Abstracts International: 1861-June 2004; reference lists of articles.

Selection criteria

Randomised Controlled Trials (RCTs) or Controlled Clinical Trials (CCTs) of interventions to improve involvement in a single consultation or an episode of primary medical care of older patients (≥ 65 years).

Data collection and analysis

Two reviewers independently assessed trial quality and extracted data.

Main results

We included four studies. Three different interventions were examined: 1. Visit preparation booklet; 2. Pre-visit session; 3. Group programme. Interventions and outcome measures were heterogeneous. Primary outcome measures were questioning behaviour, self-reported active behaviour and visit evaluation.

Three studies were randomised trials, one study had a quasi-random design. Three studies had a post-test only design. Two studies found a positive effect on question-asking because of a pre-visit session; no other obvious results were found.

Reviewers' conclusions

Overall this review gives too limited evidence to draw firm conclusions on effectiveness of specific instruments to improve involvement of older people. Reasons for this limited evidence in the field of involvement of older patients are not clear. Maybe one thinks older patients do not differ in this respect to younger patients. The results of our review compared to two reviews with younger people do not contradict. Maybe their conclusions are valid for the older population as well, but this remains uncertain.

Background

Over the past quarter of a century, societal support has grown for demands that patients should be involved collaboratively in the delivery of health care[1-3]. The case for patient involvement is based on evidence that active participation on the part of patients during the medical interview is associated with better health outcomes[4;5] and increased involvement may improve aspects of medical care[6;7]. On the other side, lack of involvement may have adverse consequences such as non-adherence to treatment, possibly with negative outcomes[8]. Besides this, the fundamental importance of patient dignity and autonomy is increasingly recognised[9], and there is a growing expectation among patients that they should be involved[10]. Accumulating empirical studies show that patients of doctors who encourage them to participate more actively in treatment decisions have more favourable health outcomes, in terms of both physiological and functional status, than those whose doctors do not[11].

Involvement

Involvement may be located at different levels: 1) involving patients/ consumers in the development of medical care and 2) involving patients in their own medical care[12]. For this review we focus on the latter and define patient involvement as enabling patients to take an active role in deciding about and planning their own primary medical care. This means supporting patients in deciding about using health care, facilitating the role of patients as their own health advocates and encouraging patients to share responsibility for their own health. Also the intention is to assist the patient to make as informed a choice as possible about the diagnosis and treatment, and about benefit and risk, and to take full part in a therapeutic alliance. The patient is able to exercise reasonable autonomy and share in the decisions for his/her medical treatment and care.

Interventions

The expected interventions to improve the involvement of patients in their own health care may focus on patients, health care providers and/or the health care system itself. The amount of doctor's time allocated for a visit obviously has some effect on the nature of the interaction[13]; this also applies for waiting lists and the accessibility of the office. Although we are aware of their importance, in this review we will exclude interventions focused on these items and those interventions focused on the health care system. Also excluded are interventions like self-help groups.

Patient-focused interventions can take place before, during or after the patient/health care provider consultation. We used a categorisation of interventions based on patients' views on health care described by Wensing and Grol[14]: interventions focused on the use of health care (giving information on appropriate use of health care, giving information to choose a care provider), interventions focused on the preparation for contact with a care provider (supplying patient data, preparation for active participation), interventions focused on contact with the care provider (providing patient tailored information; stimulating the communication strategy of shared decision-making; stimulating patient adherence) and interventions focused on feedback of care (patients' evaluations of care and procedures used for complaints and comments). Further on in this review we give concrete examples of the different categories.

Primary care and episodes of care

This review will focus on interventions which take place in primary medical care, during a patient's episode of care. Primary care is the provision of integrated, accessible health care services by clinicians who are responsible for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practising in the context of family and community[15]. Or, according to the World Organisation of Family Doctors (WONCA): primary care is the setting within a health care system, usually in the patient's own community, in which the first contact with a health professional occurs (excluding major trauma)[16]. The distinction of primary medical care is because we would like to focus on those encounters related to services and treatments of illnesses/conditions and therefore exclude preventive and health promotion activities, etc. There are many different health care providers working in primary care. For the purpose of this review we will only include studies that focus on the patients themselves or GPs (or their substitutes). Excluded are dentists, pharmacists, medical nurses, community nurses, nurse practitioners, practice nurses etc.

An episode of care refers to a series of consultations, interventions, investigations and treatments about a specific health issue, or all encounters needed for the management of a specific health problem. It is a direct encounter in which there is face-to-face meeting of patient and professional. This can be subdivided into an office encounter (a direct encounter in the health care provider's office), a home encounter (a direct encounter occurring at the patient's residence) or a hospital encounter (a direct encounter in the hospital setting). This review will focus on office encounters and home encounters. Encounters occurring

in hospitals, nursing homes and urgent care centres (which handle minor ailments with quick service and easy access), as well as indirect encounters (such as telephone calls and letters) will be excluded.

Older patients

The type of participants in this review will be older patients. Most developed countries have accepted the chronological age of 65 years as a definition of 'elderly' or older person. While this definition is somewhat arbitrary, it is often associated with the age at which one can begin to receive pension benefits[17]. For this review we will define an older patient as a patient 65 years of age or older. We use the term older patient, although there are a lot of other terms in use for older patients, like older consumer, older person, senior and so on.

In 2000 almost seven per cent of the world's population was aged 65 years or older. By 2050 it is expected that this figure will have more than doubled[18]. In addition to this population aging, more attention has to be paid to the problems and needs of older patients. Older patients often have multiple health problems. In previous studies figures vary, but it seems that at least 80% of people older than 65 have one or more chronic conditions and 65% have multiple chronic conditions[19].

Communication with some older patients is made more difficult by age-related physiological changes as well as disruptions in the social and physical environment. Impaired hearing and vision can impede communication, while deficits in mobility can lead to physician impatience with the length of interaction. Environmental changes include loss of spouse and friends, new living arrangements, and unfamiliar health care settings[13]. Besides this, some older people view the process of aging as one that is inevitably linked with disease, and therefore they may not contact the doctor with, for example, breathlessness[20].

Another difficulty might be the lack of contact with doctors older people may have had in their earlier years. A lifetime of reliance on self-care, possible language barriers, lack of experience in dealing with upper-class, usually white, practitioners[21], and a lower educational level[13] might all contribute to the fact that older people can be rather reluctant to seek help for their complaints[22] and are known to participate in their consultations less than other patient groups[11;23]. In a study by Cassileth et al[23], patients' qualitative additions to questionnaire responses illustrated their points of view. 'The layman is not qualified to make decisions,' was the older person's typical reason for rejecting participation in medical decisions. Older patients similarly justified their preference for minimal information by explaining: 'I'm not qualified'; 'I need as little to worry about as possible'; 'It's the doctor's job, he'll take care of the details.'

As well as patients, doctors also belong to age cohorts that may affect their attitudes toward older people. There are some signs that age stereotypes may affect medical care provided to older patients. Doctors may view older patients as less desirable patients, spend less time with them and respond less to their psychosocial concerns[24]. In response to this, older patients may become more unwilling to seek or continue needed treatment. In contrast, a recent international qualitative study[25] shows that GPs were positive about involving older patients in their own general practice care. GPs in this study mentioned their own lack of time, and sometimes the cognitive and physical impairments of older patients, as barriers to involvement.

In conclusion, there may be gaps in communication between older patients and doctors that potentially reduce the effectiveness of medical care by, for example, failing to address symptoms of treatable conditions that impact upon functional status and quality of life. Promoting the involvement of older patients may improve this, for example enhancing their satisfaction with care and health status[26], and improving their adherence to prescribed medication and the advice provided[27]. This review evaluated the effects of interventions aimed at improving an older patient's involvement in his/her own primary medical care. Another purpose of this review was to show the whole range of possible interventions to improve involvement of older patients in their primary care.

Objectives

The objectives of this review were: to identify interventions (assessed in a RCT or CCT) in primary medical care that improved an older patients' involvement in his/her health care, to describe the outcome measures used to assess these interventions; and to summarise their effects.

Criteria for considering studies for this review

Types of studies

- Randomised Controlled Trials (RCTs)
- Controlled Clinical Trials (CCTs)

Types of participants

Older patients (≥ 65 years), and/or their care givers/family members and/or GP (or substitute).

Types of interventions

Interventions met the following criteria:

- Focused on a single consultation or an episode of care;
- In primary medical care, concerning doctors (or their substitutes). Pharmacists, dentists, community nurses, hospitalists, etc. were excluded;
- In relation to consultations (before, during, after).

Excluded were:

- Self-help groups and interventions focused on structural aspects of care, e.g. the management of waiting times or waiting lists, appointment times, length of consultation.

Types of outcome measures

A number of processes and outcomes might be affected by interventions that aim to improve an older patient's involvement in the primary care consultation. We extracted all outcomes and grouped these into the following categories (when available):

- Knowledge and understanding (information access and use, knowledge acquisition, retention of information/ability to recall information);
- Communication (use of communication aids, communication enhancement);
- Patient involvement in care process (decision making, patient-held information);
- Evaluation of care (consumer-professional interactions experience, perceptions and ratings of care or interventions, satisfaction);
- Skills acquisition (communication skills/techniques);
- Health status and wellbeing (physical health of patient, psychological health of patient, psychosocial outcomes);
- Health behaviour (attitudes, adherence to shared decision, use of interventions or services (associated with assessment of recommended practice from clinical guidelines or their equivalent));
- Treatment outcomes (physiological measures);
- Outcomes related to health professionals (eg. knowledge, attitudes, skills, behaviour);
- Health system outcomes (eg. length of consultation).

Search strategy for identification of studies

This Cochrane review used the following search strategy as the basis to identify relevant studies. This is the search strategy that was used to search MEDLINE (Ovid) 1966-June 2004:

1. primary health care/
2. (primary care or primary medical care).tw.
3. (primary health or primary healthcare).tw.
4. general practice.tw.
5. family practice/
6. (family practice or family medicine$).tw.
7. (general practitioner$ or gp$ or general physician$).tw.
8. (family physician$ or family doctor$ or family practitioner$).tw.
9. physicians, family/
10. or/1-9
11. community health services/
12. (communit$ adj3 health).tw.
13. 11 or 12
14. 10 or 13
15. patient education/
16. ((patient$ or client$ or consumer$ or recipient$ or subject$ or care?giver$ or carer$ or famil$) adj3 (educat$ or inform$ or train$ or counsel$ or advise or advice)).tw.
17. 15 or 16
18. patient participation/
19. ((patient$ or client$ or consumer$ or recipient$ or subject$ or care?giver$ or carer$ or famil$) adj3 (participat$ or shar$ or joint or empower$ or involve$)).tw.
20. Patient-Centered Care/
21. consumer participation/
22. or/18-21
23. decision making/
24. ((patient$ or client$ or consumer$ or recipient$ or subject$ or care?giver$ or carer$ or famil$) adj3 (decision$ or consent or directive$ or choice$ or preference$)).tw.
25. informed consent/
26. advance directives/
27. or/23-26
28. communication/
29. ((patient$ or client$ or consumer$ or recipient$ or subject$ or care?giver$ or carer$ or famil$) adj3 (communicat$ or interact$ or relation$ or relate$ or attitude$)).tw.
30. physician patient relations/
31. or/28-30
32. exp Audiovisual Aids/
33. (audio$ or recording$ or video$ or tape$ or taping).tw.
34. internet/ or internet.tw.
35. computers/ or computer$.tw.
36. (patient$ adj3 (summary or summaries)).tw.
37. decision aid$.tw.

38. decision support techniques/
39. (pamphlet$ or leaflet$ or diary or diaries or sheet$ or brochure$ or booklet$).tw.
40. (cue card$ or prompt$ or checklist$).tw.
41. patient held record$.tw.
42. (pre-consultation$ or preconsultation$).tw.
43. feedback form$.tw.
44. or/32-43
45. (late life or elder$ or aged or old age or geriatric or seniors or middle age or middle aged).tw.
46. ((old or older or aging or senior) adj3 (person or people or adult$ or subject$ or patient$ or consumer$ or male$1 or female$)).tw.
47. exp aged/ or aging/ or middle age/
48. or/45-47
49. randomized controlled trial.pt.
50. controlled clinical trial.pt.
51. randomized controlled trials.sh.
52. random allocation.sh.
53. double blind method.sh.
54. single blind method.sh.
55. or/49-54
56. animal/ not (human/ and animal/)
57. 55 not 56
58. clinical trial.pt.
59. exp clinical trials/
60. (clin$ adj25 trial$).ti,ab.
61. ((singl$ or doubl$ or trebl$ or tripl$) adj25 (blind$ or mask$)).ti,ab.
62. placebos.sh.
63. placebo$.ti,ab.
64. random$.ti,ab.
65. research design.sh.
66. or/58-65
67. 66 not 56
68. 57 or 67
69. 17 or 22 or 27 or 31 or 44
70. 14 and 69
71. 70 and 48
72. limit 70 to (middle age <45 to 64 years> or "all aged <65 and over>" or "aged <80 and over>")
73. 71 or 72
74. 68 and 73

Appropriate variations of the above search strategy were utilised to search the following electronic databases:

- Cochrane Consumers and Communication Review Group Specialised Register: May 2003;
- Cochrane Central Register of Controlled Trials (CENTRAL); The Cochrane Library: The Cochrane Library issue 1, 2004;

- EMBASE: 1988-June 2004;
- PsycINFO: 1872-June 2004;
- DARE: The Cochrane Library issue 1, 2003;
- ERIC: 1966-June 2004;
- CINAHL: 1982-June 2004;
- Sociological Abstracts: 1963-June 2004;
- Dissertation Abstracts International: 1861-June 2004.

Other search strategies

We tried to identify additional studies by searching the reference lists of relevant trials and reviews identified. Finally we examined our personal literature collections to identify relevant studies.

Methods of the review

Selection of trials

The titles and/or abstracts of the studies identified by the search were inspected by two reviewers independently to see whether the articles were likely to be relevant. In case of disagreement between the two reviewers or when it not became clear from the abstract whether a study was relevant or not, the full article was obtained.

We obtained the full text of all possibly relevant studies for independent assessment by two reviewers. Articles were categorised in three groups: 1) background literature, 2) possibly included studies and 3) excluded studies. Included studies had to fulfil all four inclusion criteria, which were:

- Study design: RCT or CCT;
- Setting: primary medical care: doctors;
- Participants: older patients (≥ 65 years);
- Intervention: the study included at least one intervention focusing on older patients that aimed to increase their involvement in their primary medical care consultation.

We also required that the articles described the content and process of the intervention. A standardised data extraction form was used.

Assessment of methodological quality

The methodological quality of the trials possibly included in this review were assessed independently by the same two reviewers who did the selection of the trials, using the criteria described in the Cochrane Handbook[28], which are based on the evidence of a strong relationship between the potential for bias in the results and the allocation concealment, and are defined as:

A. Adequate concealment of treatment allocation: e.g. randomisation from serially numbered, opaque sealed envelopes, third party or computer (low risk of bias);

B. Some doubt about the concealment of treatment allocation or unclear (moderate risk of bias);

C. Inadequate concealment of the treatment allocation: e.g. tossed coins or approached patients on alternate days (high risk of bias);

D. Concealment of allocation was not used.

Trials were included when they met criteria A or B. In addition we used the Jadad Scale (Table 1) as a rough measure of study design and reported quality.

Table 1 Items of Jadad scale

Was the study described as randomized (this includes words such as randomly, random, and randomization)?
Was the method used to generate the sequence of randomization described and appropriate (table of random numbers, computer-generated, etc)?
Was the study described as double blind?
Was the method of double blinding described and appropriate (identical placebo, active placebo, dummy, etc)?
Was there a description of withdrawals and dropouts?

Data extraction

The following data was extracted from relevant studies by one reviewer and checked by a second reviewer using a data collection form: Methods (Objective, Study Design, Recruitment, Randomisation, Clinician blind, Assessor blind, Patient awareness of study, Total number approached, Number agreed to participate, Methods of analysis), Participants (Country, Diagnosis, Age, Sex, Ethnicity, Exclusions, Clinical setting), Interventions (Consultation type, Intervention intervention group, Intervention control group, N baseline, Theoretical basis), Outcomes (Timing of outcome assessment, outcomes), Notes (Power calculation) and Allocation concealment. Disagreements were discussed between the reviewers. Data was entered into RevMan by one

reviewer. Whenever details of methodology were not available we did not attempt to contact the authors of included studies for additional information.

Data analysis

We considered combining the studies quantitatively once we had completed the search. However, the diversity of interventions and outcome measures used in the studies made this impossible. A structured review of the studies was therefore undertaken. Throughout the review process reviewers were not blinded to the trials.

Description of studies

In this section we describe the studies included in the review; the characteristics of the interventions; the characteristics of the participants; and the types of outcomes measured. Electronic searching identified 9716 titles and abstracts (search until 01-06-04). In total, 88 of these were judged to potentially meet the entry criteria and the full articles were retrieved for further detailed assessment. Finally, we included four studies[29-32]. These studies were published in English and conducted in the USA.

Characteristics of the interventions

Three different interventions were examined. Two studies used a combined intervention[29;31], and two studies used one type of intervention[30;32]. The following specific interventions were examined:

1. Visit preparation booklet

Three studies[29;31;32] included a 'visit preparation booklet' in their intervention. The booklets consisted of lists of patients' concerns, sample questions for discussions and suggestions for preparing and checking information.

2. Pre-visit session

Two studies[29;30] arranged a pre-visit session in which patients received help in formulating questions, and making an order for presenting them.

3. Group programme

One study[31] arranged a 2-hour group programme about patient behaviour, it included modeling of both undesirable and desirable patient behaviours. This took place up to three months before the physician visit. Detailed descriptions of the interventions appear in the Characteristics of Included Studies table.

Table Detailed characteristics of included studies

Study	Methods	Participants	Interventions	Outcomes	Notes	Allocation concealment
Cegala 2001	Study design: quasi-experimental design involving two intervention conditions Allocation procedure: partly patients were randomly selected from appointment records, and randomly assigned to intervention condition. Another part of untrained patients were selected from the waiting room. Physicians were blinded to intervention / control condition.	Age: ≥ 65 years Setting: Family Practice Center	Trained intervention condition: (n=16) Training booklet by mail, approx. 3 days before appointment Face-to-face session, 30-minutes, just before physician visit Untrained intervention condition: (n=17) brief pre-visit questionnaire	Questioning behaviour	Trained patients asked more questions about medically related topics than did untrained patients Trained patients elicited more information than did untrained patients Trained patients obtained more information per question asked than did untrained patients Trained patients provided more information than did untrained patients	B
Kimberlin 2001	Study design: post-test only experimental design Allocation procedure: Patients were alternately assigned to intervention or control group after a coin toss determined each day's first patient assignment Physicians were blinded to intervention / control condition. Outcome assessors were blinded to intervention / control condition.	Age: ≥ 65 years Additional inclusion criteria: taking medication to treat chronic conditions and who were caring for themselves Setting: Ambulatory care family practice outpatient centre	Intervention group: Pre visit interview to help to formulate questions about current therapy, questions were written down Control group: (n=23) No details provided	Questioning behaviour	Subjects in intervention group were more likely to ask questions of physicians than were subjects in the control group Intervention group patients asked qualitatively different questions	B

Continued table Detailed characteristics of included studies

Study	Methods	Participants	Interventions	Outcomes	Notes	Allocation concealment
Tennstedt 2000	Study design: randomized trial, posttest-only design. Allocation procedure: randomization occured at the site level. Intention to treat analysis: yes	Age: ? (mean age: 77) Setting: community sites (senior housing, senior centers)	Intervention condition: (n=155) Two hour group program about patient behaviour in which were given: - Cue cards with desirable behaviour - Preparation booklet, to record and prioritize reasons for the physician visit Control condition: (n=200) No group-program (usual care)	Active behaviour-Satisfaction	Trend towards more targeted behaviour by those in intervention group ($p<0.08$) Intervention patients were more likely to bring in a list of problems and questions to physician visit No differences in satisfaction (except for interpersonal satisfaction) Second analysis showed significant more active behaviour among intervention patients (those who attended the program)	B
Wilkinson 2002	Study design: RCT Allocation procedure: patients were randomly assigned to one of two groups	Mean age of total population: approx. 60 years Setting: Primary care visits of the Southern Arizona Veterans Affairs Health Care System (SAVAHCS)	Intervention group:- Prior to their vist: appointment guidebook (incl. appointment list, suggestions for getting ready for the appointment, instructions for the day of the appointment, sample phrases to assist in discussing issues, suggestions for completing the visit, notes) Control group:- Standard letter about upcoming appointment	Visit evaluation (preparedness, self-effectiveness, visit effectiveness)-Guidebook evaluation-VHA chronic disease and prevention indicators	- No differences in experience of primary care visit effectiveniss were detected between intervention and control group-59% of intervention patients were able to use the guidebook during the appointment - Intervention group patients received more often influenza and pneumococcal vaccinations; control group patients received more often gender-specific cancer screening and prostate cancer screening education.	B

Participants

The four studies included older patients visiting doctors working in primary medical care. One study added additional inclusion criteria[30], namely patients had to take medication. Not all studies specified patients' demographics of the different groups. One study noted that the composition of both groups was 93% male, and the average age of the population which they selected from was approximately 60 years[32]. In order to gain evidence, we decided to include this study as well, although the age criterion is not entirely answered; no other studies came this close to our age criterion. One study noted that participants were mainly women (83%), with an average age of 77,4 years[31]. One study selected patients over the age of 64, but did not describe mean age of participating population[30]. The last study provided detailed data about patient demographics. Mean age in both groups around 72 years; 56% males in trained group, 29% males in untrained group[29].

Outcome measures

Two studies had questioning behaviour of patients as their primary outcome measure[29;30]. One study had self-reported active behaviour as their primary outcome measure[31] and one study made visit evaluation (preparedness, self-effectiveness and visit effectiveness) their primary outcome measure[32]. Secondary outcomes were satisfaction with the patient visit[31], and chronic disease and prevention indicators[32].

Methodological quality of included studies

Study design

Three studies were randomised trials, one study had a quasi-random design (they alternately assigned to one of two groups)[30]. However, three studies had a post-test only design[30-32]. In one study this design was chosen because of concerns that pretesting would sensitize respondents to the objectives of the study and might affect their behaviour in subsequent medical visits[31]. The other studies did not specify reasons for a post-test only design.

Method of allocation

Two studies described their allocation procedure no more than that they randomised subjects to one of two groups[31;32]. One study randomly selected patients and randomly assigned them to one of two groups, in addition they

selected control patients from the waiting room[29]. One study alternately assigned to one of two groups, after a coin toss determined each day's first assignment[30].

Blinding

In two studies outcome assessors and physicians were blinded to the intervention condition[29;30]. In the other two studies blinding was either not described or unclear[31;32]. These studies' intervention conditions had aspects that cannot be easily blinded (cue cards, preparation booklet, appointment guidebook).

Use of intention to treat analysis

One study described that they performed an intention to treat analysis, besides a sensitivity-analysis[31]. The other three studies did not describe the type of analysis they performed[29;30;32]. The number of analysed participants was respectively 16 and 17[29]; 22 and 23[30]; 155 and 200[31]; and 43 and 73[32]. Where in the last study the response percentages from the original participants were 31% and 54% respectively.

Baseline measurement

Three studies did not include a baseline measurement[30-32]. One study gave patients a brief pre-interview questionnaire[29].

Results

In this section we report on the results of the included studies. Results of interventions were grouped into two categories, health behaviour and evaluation of care.

Health behaviour

Three studies had behaviour (questioning behaviour or active behaviour) as an outcome measure[29-31]. One study showed that trained (intervention) patients asked more questions ($p=0.01$), elicited more information ($p=0.05$), obtained more information per question ($p=0.04$) and provided more information ($p=0.001$) compared to untrained (control) patients[29]. An identical result was found in the next study: intervention group patients were more likely to ask questions ($p<0.001$) and they asked qualitatively different questions compared

to control patients[30]. Percentages of patients who asked questions about test or treatment varied, in one study 64% of the intervention group asked questions, compared to 35% in the control group[30]; another study showed overall that 26% asked questions[31].

The last study showed that self-reported active behaviour did not improve in intervention patients in the intention-to-treat analysis. Of all participants in this study 30% stated their preference about treatment or test during the visit, however, 21% stated that their doctor dominated the encounter. A sensitivity analysis of this study showed a significant greater number of self-reported active behaviour during the doctor visit ($p<0.05$) among intervention programme attenders ($n=114$)[31]. Other significant correlates of active behaviours included younger age ($p<0.001$) and female gender ($p<0.01$).

When preparation of consultations was concerned, two studies provided data, one study showed that 77% of all participants had done nothing to prepare the visit[31]; whereas 87% of all participants in another study (strongly) agreed that they were prepared for their appointment with the provider[32]. More specific: 54% had not identified specific issues to discuss before the visit and over 80% did not bring a list of questions nor asked questions[31].

Evaluation of care

Two studies had patients' evaluation of doctor visit as an outcome measure[31;32]. No differences in overall satisfaction or evaluation of doctor visit were found. However, one study found a significant difference in the satisfaction with the interpersonal aspects of the visit ($p<0.05$)[31].

More specific data about satisfaction from one study was available; 77,5% of all patients did not leave the appointment with unresolved issues, 88,7% stated that the provider listened to what they had to say and 76,2% stated that they were involved in making decisions about their care and treatment during the appointment[32].

Other patient outcomes

One study included VHA chronic disease and prevention indicators as an outcome measure[32]; which showed that intervention group patients received more often influenza and pneumococcal vaccinations and control group patients received more often gender-specific cancer screening and prostate screening education.

Discussion

This review identified four studies that evaluated interventions to improve older patients' involvement in their episodes of care. This review showed the range of possible interventions to improve involvement of older patients in their primary care. There is not enough evidence to conclude on the effectiveness of these interventions.

Low number of studies

Although we performed a highly sensitive search in order not to overlook interventions, it was striking to see the low number of studies we could include. Meaning, there is very little evidence about interventions and their effect on improving involvement of older patients in general practice care. There has been written a lot about involvement, but there is not a large amount of research knowledge about involving older patients. This seems strange, as older peoples' needs and morbidity makes them large consumers of health care[33]. There is some evidence about involving the younger age group, but this group has less needs and less morbidity and therefore less use of health care. Is involving older patients ideology or is our review too restricted, for example are the exclusion critera we chose too narrow? A lot of studies were excluded on the basis of the content of the intervention. Many studies evaluated health-assessment, reminder or preventive oriented interventions, which we considered not to be about involvement of patients. The range of interventions we identified was narrow. As is shown in the table of characteristics of excluded studies, we excluded no intervention studies exclusively on the basis of their methodology. Fifteen studies were excluded exclusively on the basis of our age criterium[34-48]; other studies were excluded on the basis of a selected group (for example, non primary medical care) of patients, or a combination of the previous mentioned. If we would have lowered our age inclusion criterium to 50 years of age, we possibly could have included another two studies[35;39]. Therefore, our conclusion is, that our inclusion criteria were not too narrow, there is just little evidence about involving older patients.

Effectiveness of interventions

If we look at reviews not specifically about elderly, what are their conclusions about effect of interventions on the process of consultations and could these conclusions be valid for older people too? For example, Harrington shows in his recent review that the interventions they reviewed had the effect of

encouraging patients to be more active in their consultations[49]. Furthermore their results on question asking were unambiguous. Griffins' review shows that in three quarters of the studies the process of consultation significantly improved, in two studies a part of the process significantly deteriorated according to patients, with the remark that in one of these two studies another process significantly favoured the intervention[50]. Could these results be valid for the old age group as well? Our results are more or less similar to the previous mentioned reviews when the influence of interventions on the process of consultations is considered. So at least there seem no contradictions in the results.

Outcome measures

When we look at patient outcomes, it is noteworthy that the included studies except one only used subjective, self- / patient- reported outcome measures. None included health status or well-being as an outcome measure. One study examined chronic disease and prevention indicators[32]. The studies included by Griffin and into a lesser extent also by Harrington did include objective health outcomes, besides subjective health outcomes and satisfaction.

How does this fit into the context of current clinical practice?

The lack of strong evidence does not justify the recommendation to implement these interventions into current clinical practice. In our opinion there should be a balance in stimulating active participation of patients and respecting their autonomy.

Factors affecting interpretation of review findings

(1) Three studies had post tests only, the fourth study did not include pre-test in evaluation of post test data. This could have interfered with the results, although some reasoning for chosing post-test only might be justified: i.e. not to sensitize respondents of control condition.

(2) In one study there were low response rates mainly in the intervention group[32] which may have lead to a more positive view of those responding patients.

(3) The number of patients in two studies were too low[29;30] to come with firm conclusions.

(4) As already mentioned, the comparison of studies is difficult because of the heterogeneity in outcome measures.

Reviewers' conclusions

Implications for practice

Overall this review gives too limited evidence to draw firm conclusions on effectiveness of specific instruments to improve involvement of older people. We cannot recommend to use the examined interventions in daily practice. The reasons for less evidence in the field of involvement of older patients is not clear, maybe one thinks older patients do not differ in this compared to younger patients. In our introduction we tried to make clear that we think older patients should be approached differently. The results of our review compared to two reviews with younger people do not contradict. Maybe their conclusions are valid for our population as well, but we are not sure. As there is limited evidence it is difficult to give guidelines for daily practice, we think that there should be a balance in respecting patients' autonomy and stimulating their active participation in their own care.

Implications for research

However, the evidence does also not justify to fully ignore these kind of interventions. In order to conclude on the effectiveness of these interventions further research is needed. This future research may focus on pre-visit interventions including a face-to-face session, supported with a written element as this package seems one of the most promising methods to involve older patients in their care. The studies should be randomised trials with a complete design (not post-test only), appropriate number of older patients and should preferably include objective health outcomes besides a measure for involvement. This measure for involvement may be a combination of patients' self-reported behaviour and patients' self-reported evaluation, but should maybe also include an objective observation of patients' involvement.

Table of excluded studies

Study	Reason for exclusion
Asch 1991[51]	Patient criteria not met: Participants age range 17-58 years
	Setting not met: Psychiatric outpatient clinic
Banks 1998[52]	Patient criteria not met: women 15-80
	Intervention criteria not met: health education intervention
Beck 1997[53]	Intervention criteria not met: not focused on episodes of care; not focused on improvement of involvement
Begley 1997[54]	Intervention criteria not met: pharmacy based intervention
Bernabei 1998[55]	Intervention criteria not met: case management programme
Bernsten 2001[56]	Intervention criteria not met: pharmacy based intervention
Bertakis 1991[34]	Patient criteria not met: Participants all ages
Billault 1995[35]	Patient criteria not met: Participants mean age 51-55
Billip 2001[57]	Intervention criteria not met: Intervention focused at improving loneliness
Boston 2001[58]	Intervention criteria not met: Intervention not focused on improving involvement
	Design not met: prospective non-randomised comparative study
Cegala 2000a[37]	Patient criteria not met: Participants mean age 43-46
Cegala 2000b[36]	Patient criteria not met: Participants mean age 43-46
Cornbleet 2002[38]	Patient criteria not met: Participants 18+
Davison 1999[39]	Patient criteria not met: Participants age 50-79
Demiris 2003[59]	Design not met: No trial
	Intervention criteria not met: virtual visits for chronic patients
Dietrich 1989[60]	Intervention criteria not met: Intervention consisted of reminders
Drury 2000[61]	Patient criteria not met: Participants aged 16+, selected patients: radiotherapy outpatients
Dubbert 2002[62]	Patient criteria not met: Participants > 60
	Intervention criteria not met: Intervention was not focused on enhancing involvement
Edworthy 1999[63]	Patient criteria not met: Participants 50+
	Intervention criteria not met: computer assisted educational intervention to facilitate appropriate utilization of an antiinflammatory medication
Ersek 2003[64]	Intervention focused on self-management of pain
Gabbay 2003[65]	Patient criteria not met: age range 18-79; selected subjects: depression
	Design not met: part of a trial, intervention not aimed at improving involvement

Gagnon 1999[66]	Patient criteria not met: Selected group of participants
	Intervention criteria not met: nurse case management intervention
Greenberger 2003[67]	Design not met: cross-sectional study
	Intervention criteria not met: no intervention
Groessl 2000[68]	Patient criteria not met: Participants > 60; selected group of patients: osteoarthritis
	Intervention not met: intervention focused on improvement of living with OA
Hainsworth 2003[69]	Patient criteria not met: selected group of patients: arthrits
	Design not met: no control group
Hall 1992[70]	Intervention criteria not met: Intervention that supplies extra care
Hershey 2002[71]	Patient criteria not met: Participants mean age 41-52
	Intervention criteria not met: Intervention about history questionnaire
Hickson 2003[72]	Patient criteria not met: Participants age 56-93
	Intervention focused on health promotion, not on involvement
Holland 2003[73]	Design not met: no trial
	Intervention criteria not met: health coaching program
Hornberger 1997[40]	Patient criteria not met: 18 years and older
Kerse 1999[74]	Intervention criteria not met: health promotion intervention focused on GPs
Kidd 2004[75]	Patient criteria not met: all patients attending diabetic clinic at a hospital
King 2002[76]	Patient criteria not met: selected participants (only women, aged 49-82 year)
	Intervention criteria not met: exercise training
Kobb 2003[77]	Design criteria not met: no trial
	Intervention criteria not met: not focused on involvement
Kralik 2004[78]	Design not met: no trial; exploration concept self-management among chronic patients
	Intervention not met: no intervention
Krishna 1997[79]	Design not met: Review of trials
Lecouturier 2002[80]	Patient criteria not met: selected group of patients (colon/ lung cancer; all ages)
Letts 2003[81]	Design not met: no trialIntervention not
Liaw 1997[41]	Patient criteria not met: all ages
Little 2001[43]	Patient criteria not met: all ages
Little 2004[42]	Patient criteria not met: all ages
Lorig 2001[82]	Patient criteria not met: participants 40+ with certain chronic diseases

Lorig 2003[83]	Patient criteria not met: selected group of patients, hispanics with chronic diseases (heart, lung disease of type 2 diabetes)
Maly 1999[44]	Patient criteria not met: Participants aged 19-75 years
Matuska 2003[84]	Design not met: no trial; intervention focused at participation in occupations not in health care
McCann 1996[45]	Patient criteria not met: ages 16-74
McGilton 2003[85]	Patient criteria not met: residents of nursing home units
	Intervention criteria not met: relationship enhancing
McKinstry 2000[86]	Intervention criteria not met: no intervention
	Design not met: no trialPatient criteria not met: all ages
Miaskowski 2004[87]	Intervention criteria not met: intervention focused at pain control
Mundinger 2000[88]	Intervention criteria not met: comparison nurse practitioner and physician
Murray 2001a[89]	Patient criteria not met: selected subjects, women (mean age 50)
	Intervention criteria not met: disease specific decision aid
Murray 2001b[90]	Patient criteria not met: selected subjects, men (mean age 63)
	Intervention criteria not met: disease specific decision aid
Newbury 2001[91]	Intervention criteria not met: Health assessment programme
Oermann 2003a[92]	Intervention criteria not met: focused on health-promotion teaching instead of involvement.
	Patient criteria not met: selected participants (university medical centers)
Oermann 2003b[93]	Intervention criteria not met: not focused on involvement
Oermann 2003c[94]	Intervention criteria not met: not focused on involvement
	Design not met
Parry 2003[95]	Intervention criteria not met: interdisciplinary team intervention
Penner 1991[96]	Intervention criteria not met: reminder study
	Design not met
	Patient criteria not met: subjects aged 60+
Post 2001[46]	Patient criteria not met: Participants mean age 42-47
Pugh 1999[97]	Patient criteria not met: in-hospital patients, selected patients (CHF)
	Intervention criteria not met: case management
Radecki 1999[98]	Patient criteria not met: Participants 18 or older
	Intervention criteria not met: Pain Tracker
Reavley 1991[99]	Patient criteria not met: Participants 18+; selected group of patients (with anxiety disorder)
Reed 2004[100]	Design not met: review, about partnership in research
Reuben 1999[101]	Intervention criteria not met: Comprehensive assessment study
Roter 1977[47]	Patient criteria not met: Participants median age 50 years

Rubenstein 1994[102]	Ineligible study design: Baseline measurement of a CGA
Sahar 2003[103]	Intervention criteria not met: not focused on involvement
Saunders 2003[104]	Intervention criteria not met: health promotion study
Savage 1990[48]	Patient criteria not met: Participants aged 16-75
Schraeder 2001[105]	Intervention criteria not met: Intervention was not focused on enhancing involvement
Sidani 2003[106]	Design not met.
Sommers 2000[107]	Intervention criteria not met: Multidisciplinary team intervention
Stump 1995[108]	Patient criteria not met: Participants 50+; mean age 67
	Design not met: no trial, no intervention.
Sturgess 2003[109]	Intervention criteria not met: pharmacy based intervention
Thom 1999[110]	Patient criteria not met: Participants all adult patients
	Intervention not focused on involvement, but on trust
Thom 2000[111]	Patient criteria not met: Participants mean age 47
	Intervention not focused on involvement, but on trust
Toseland 1992[112]	Patient criteria not met: Participants > 59
	Intervention not focused on involvement, but on support of spouses
Tsay 2004[113]	Patient criteria not met: selected group of patients (end-stage renal disease); all ages
Von Korff 1998[114]	Patient criteria not met: subjects aged 25-70
	Intervention criteria not met: Intervention disease specific
Wasson 1984[115]	Patient criteria not met: Participants 55+
	Intervention criteria not met: provider continuity; not focused on involvement
Wasson 1999[116]	Intervention criteria not met: more assessment study than focused on involvement
Waxman 2003[117]	Patient criteria not met: 60+
	Intervention not focused on involvement: self-management footcare program
Whatley 2002[118]	Intervention criteria not met: Study was about presenting information
Williams 1998[119]	Patient criteria not met: all patients
	Intervention not focused on involvement, but on preventive health care
Williams 2001[120]	Patient criteria not met: Participants 18+; selected group: patients with cancer

References

1 Griffiths R. NHS Management Inquiry. HMSO London 1983;9.
2 Weiss DJ. Consensual norms regarding patient involvement. Soc Sci Med 1986; 22:489-96.
3 Williams B. Patient satisfaction: a valid concept? Soc Sci Med 1994; 38:509-16.
4 Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989; 27:S110-S123.
5 Kaplan SH, Greenfield S, Gandek B, Rogers WH, Ware JE Jr. Characteristics of physicians with participatory decision-making styles. Ann Intern Med 1996; 124:497-504.
6 Atkin PA, Stringer RS, Duffy JB, Elion C, Ferraris CS, Misrachi SR, Shenfield GM. The influence of information provided by patients on the accuracy of medication records. Med J Aust 1998; 169:85-8.
7 Liaw T, Lawrence M. Rendall J. The effect of computer-generated patient-held medical record summary and/or a written personeal health record on patients' attitudes, knowledge and behaviour concerning health promotion. Fam Pract 1996; 13:289-93.
8 Bibowski RM, Ripsin CM, Lorraine VL. Physician-patient congruence regarding medication regimes. J Am Geriatr Soc 2001; 49:1353-7.
9 Lothian K, Philp I. Care of older people: maintaining the dignity and autonomy of older people in the health care setting. BMJ 2001; 322:668-70.
10 Verhoef MJ, White MA, Doll R. Cancer patients' expectations of the role of family physicians in communication about complementary therapies. Cancer Prev Control 1999; 3:181-7.
11 Kaplan SH, Gandek B, Greenfield S, Rogers W, Ware JE. Patient and visit characteristics related to physicians' participatory decision-making style. Results from the Medical Outcomes Study. Med Care 1995; 33:1176-87.
12 Wensing M, Baker R. Patient involvement in general practice care: a conceptual framework. Eur J Gen Pract 2003; 9:62-5.
13 Haug MR, Ory MG. Issues in elderly patient-provider interactions. Res Aging 1987; 9:3-44.
14 Wensing M, Grol R. Patients' views on health care. A driving force for improvement in disease management. Dis Manage Health Outcomes 2000; 7: 117-25.
15 Vanselow NA, Donaldson MS, Yordy KD. A new definition of primary care. JAMA 1995; 273:192.
16 WONCA Europe 2002. The European definition of general practice/family medicine.
17 World Health Organization 2003. Information needs for research, policy and action on ageing and older persons: definition of an older or elderly person. http://www3.who.int/whosis/mds/mds_definition/mds_definition_english.cfm?path=whosis,search,mds,mds_definition&language=english
18 United Nations, Population Division, Department of Economic and Social Affairs. Second World Assembly on Ageing: population ageing 2002 [chart].
19 Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Arch Intern Med 2002; 162:2269-76.

20 Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. Br J Gen Pract 1997; 47:427-30.
21 Haug MR. Doctor-patient relationships and their impact on self care of the elderly. Self care and health behavior in old age. Croom Helm 1986.
22 Foster J, Dale J, Jessopp L. A qualitative study of older people's views of out-of-hours services. Br J Gen Pract 2001; 51:719-23.
23 Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. Ann Intern Med 1980; 92:832-6.
24 Giles H, Coupland N, Wiemann JM. Communication, health and the elderly. Manchester University Press in association with The Fulbright Commission 1990; 8.
25 Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R, on behalf of Improve Research group. GPs' views on involvement of older patients: a European qualitative study. Patient Educ Couns 2004; 53:183-8.
26 Rodin J. Aging and health: effects of the sense of control. Science 1986; 233:1271-6.
27 Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998; 36:1138-61.
28 Clarke M, Oxman AD, editors. Cochrane Reviewers' Handbook 4.1.5 [updated April 2002]. In: The Cochrane Library. The Cochrane Collaboration. Oxford: Update Software; 2002, issue 2
29 Cegala DJ, Post DM, McClure L. The effects of patient communication skills training on the discourse of older patients during a primary care interview. J Am Geriatr Soc 2001; 49:1505-11.
30 Kimberlin C, Assa M, Rubin D, Zaenger P. Questions elderly patients have about on-going therapy: a pilot study to assist in communication with physicians. Pharm World Sci 2001; 23:237-41.
31 Tennstedt SL. Empowering older patients to communicate more effectively in the medical encounter. Clin Geriatr Med 2000; 16:61-70.
32 Wilkinson CR, Williams M. Strengthening patient-provider relationships. Lippincotts Case Manag 2002; 7:86-102.
33 Fryer GE, Green LA, Dovey SM, Yawn BP, Phillips RL, Lanier D. Variation in the Ecology of Medical Care. Ann Fam Med 2003; 1:81-9.
34 Bertakis KD. Impact of a patient education intervention on appropriate utilization of clinic services. J Am Board Fam Pract 1991; 4:411-8.
35 Billault B, Degoulet P, Devries C, Plouin PF, Chatellier G, Menard J. Use of a standardized personal medical record by patients with hypertension: a randomized controlled prospective trial. MD Comput 1995; 12:31-5.
36 Cegala DJ, Marinelli T, Post D. The effects of patient communication skills training on compliance. Arch Fam Med 2000; 9:57-64.
37 Cegala DJ, McClure L, Marinelli TM, Post DM. The effects of communication skills training on patients' participation during medical interviews. Patient Educ Couns 2000; 41:209-22.
38 Cornbleet MA, Campbell P, Murray S, Stevenson M, Bond S. Patient-held records in cancer and palliative care: a randomized, prospective trial. Palliat Med 2002; 16:205-12.

39 Davison BJ, Kirk P, Degner LF, Hassard TH. Information and patient participation in screening for prostate cancer. Patient Educ Couns 1999; 37:255-63.
40 Hornberger J, Thom D, MaCurdy T. Effects of a self-administered previsit questionnaire to enhance awareness of patients' concerns in primary care. J Gen Intern Med 1997; 12:597-606.
41 Liaw ST, Radford AJ, Maddocks I. The impact of a computer generated patient held health record. Aust Fam Physician 1998; 27:S39-S43.
42 Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J et al. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ: published 13 February 2004. doi:10.1136/bmj.37999.716157.44.43.
43 Little P, Somerville J, Williamson I, Warner G, Moore M, Wiles R, George S, Smith A, Peveler R. Randomised controlled trial of self management leaflets and booklets for minor illness provided by post. BMJ 2001; 322:1-5.
44 Maly RC, Bourque LB, Engelhardt RF. A randomized controlled trial of facilitating informationg giving to patients with chronic medical conditions: effects on outcomes of care. J Fam Pract 1999; 48:356-63.
45 McCann S, Weinman J. Empowering the patient in the consultation: a pilot study. Patient Educ Couns 1996; 27:227-34.
46 Post DM, Cegala DJ, Marinelli TM. Teaching patients to communicate with physicians: the impact of race. J Natl Med Assoc 2001; 93:6-12.
47 Roter DL. Patient participation in the patient-provider interaction: the effects of patient question asking on the quality of interaction, satisfaction and compliance. Health Educ Monogr 1977; 5:281-315.
48 Savage R, Armstrong D. Effect of a general practitioner's consulting style. BMJ 1990; 301:968-70.
49 Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns 2004; 52:7-16.
50 Griffin SJ, Kinmonth AL, Veltman MWM, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. Ann Fam Med 2004; 2: 595-608.
51 Asch R, Price J, Hawks G. Psychiatric out-patients' reactions to summary letters of their consultations. Br J Med Psychol 1991; 64:3-9.
52 Banks JC, Howie JG. Reducing consultations for symptoms of cystitis using a health education leaflet. Br J Gen Pract 1998; 48:1595-6.
53 Beck A, Scott J, Williams P, Robertson B, Jackson D, Gade G, Cowan P. A randomized trial of group outpatient visits for chronically ill older HMO members: the Cooperative Health Care Clinic. J Am Geriatr Soc 1997; 45:543-9.
54 Begley S, Livingstone C, Hodges N, Williamson V. Impact of domiciliary pharmacy visits on medication management in an elderly population. Int J Pharm Pract 1997; 5:111-21.
55 Bernabei R, Landi F, Gambassi G, Sgadari A, Zuccala G, Mor V, Rubenstein LZ, Carbonin P. Randomised trial of impact of model of integrated care and case management for older people living in the community. BMJ 1998; 316:1348-51.
56 Bernsten C, Bjorkman I, Caramona M, Crealey G, Frokjaer B, Grundberger E, et al; Pharmaceutical care of the Elderly in Europe Research (PEER) Group.

Improving the well-being of elderly patients via community pharmacy-based provision of pharmaceutical care: a multicentre study in seven European countries. Drugs Aging 2001; 18:63-77.

57 Billipp SH. The psychosocial impact of interactive computer use within a vulnerable elderly population: a report on a randomized prospective trial in a home health care setting. Public Health Nurs 2001; 18:138-45.

58 Boston NK, Boynton PM, Hood S. An inner city GP unit versus conventional care for elderly patients: prospective comparison of health functioning, use of services and patient satisfaction. Fam Pract 2001; 18:141-8.

59 Demiris G, Speedie S, Finkelstein S, Harris I. Communication patterns and technical quality of virtual visits in home care. J Telemed Telecare 2003; 9:210-5.

60 Dietrich AJ, Duhamel M. Improving geriatric preventive care through a patient-held checklist. Fam Med 1989; 21:195-8.

61 Drury M, Yudkin P, Harcourt J, Fitzpatrick R, Jones L, Alcock C, Minton M. Patients with cancer holding their own records: a randomised controlled trial. Br J Gen Pract 2000; 50:105-10.

62 Dubbert PM, Cooper KM, Kirchner KA, Meydrech EF, Bilbrew D. Effects of nurse counseling on walking for exercise in elderly primary care patients. J Gerontol A Biol Sci Med Sci 2002; 57:733-40.

63 Edworthy SM, Devins GM. Improving medication adherence through patient education distinguishing between appropriate and inappropriate utilization. J Rheumatol 1999; 26:1793-801.

64 Ersek M, Turner JA, McCurry SM, Gibbons L, Kraybill BM. Efficacy of a self-management group intervention for elderly persons with chronic pain. Clin J Pain 2003; 19:156-67.

65 Gabbay M, Shiels C, Bower P, Sibbald B, King M, Ward E. Patient-practitioner agreement: does it matter? Psychol Med 2003; 33:241-52.

66 Gagnon AJ, Schein C, McVey L, Bergman H. Randomized controlled trial of nurse case management of frail older people. J Am Geriatr Soc 1999; 47:1118-24.

67 Greenberger H, Litwin H. Can burdened caregivers be effective facilitators of elder care-recipient health care? J Adv Nurs 2003; 41:332-41.

68 Groessl EJ, Cronan TA. A cost analysis of self-management programs for people with chronic illness. Am J Community Psychol 2000; 28:455-80.

69 Hainsworth J, Barlow J. The training experiences of older, volunteer lay leaders on an arthritis self-management course. Health Educ J 2003; 62:266-77.

70 Hall N, De Beck P, Johnson D, Mackinnon K, Gutman G, Glick N. Randomized trial of a health promotion program for frail elders. Can J Aging 1992; 11:72-91.

71 Hershey CO, Grant BJ. Controlled trial of a patient-completed history questionnaire: effects on quality of documentation and patient and physician satisfaction. Am J Med Qual 2002; 17:126-35.

72 Hickson L, Worrall L. Beyond hearing aid fitting: improving communication for older adults. Int J Audiol 2003; 42:S84-S91.

73 Holland SK, Greenberg J, Tidwell L, Newcomer R. Preventing disability through community-based health coaching. J Am Geriatr Soc 2003; 51:265-9.

74 Kerse NM, Flicker L, Jolley D, Arroll B, Young D. Improving the health behaviours of elderly people: randomised controlled trial of a general practice education programme. BMJ 1999; 319:683-7.

75 Kidd J, Marteau TM, Robinson S, Ukoumunne OC, Tydeman C. Promoting participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. Patient Educ Couns 2004; 52:107-12.
76 King AC, Baumann K, O'Sullivan P, Wilcox S, Castro C. Effects of moderate-intensity exercise on physiological, behavioral, and emotional responses to family caregiving: a randomized controlled trial. J Gerontol A Biol Sci Med Sci 2002; 57A:26-36.
77 Kobb R, Hilsen P, Ryan P. Assessing technology needs for the elderly: finding the perfect match for home. Home Healthc Nurse 2003; 21:666-73.
78 Kralik D, Koch T, Price K, Howard N. Chronic illness self-management: taking action to create order. J Clin Nurs 2004; 13:259-67.
79 Krishna S, Balas EA, Spencer DC, Griffin JZ, Boren SA. Clinical trials of interactive computerized patient education: implications for family practice. J Fam Pract 1997; 45:25-33.
80 Lecouturier J, Crack L, Mannix K, Hall RH, Bond S. Evaluation of a patient-held record for patients with cancer. Eur J Cancer Care 2002; 11:114-21.
81 Letts L. Occupational therapy and participatory research: a partnership worth pursuing. Am J Occup Ther 2003; 57:77-87.
82 Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW Jr, Bandura A, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 2001; 39:1217-23.
83 Lorig KR, Ritter PL, Gonzalez VM. Hispanic chronic disease self-management: a randomized community-based outcome trial. Nurs Res 2003; 52:361-9.
84 Matuska K, Giles HA, Flinn N, Neighbor M, Bass HJ. Outcomes of a pilot occupational therapy wellness program for older adults. Am J Occup Ther 2003; 57:220-4.
85 McGilton KS, O'Brien Pallas LL, Darlington G, Evans M, Wynn F, Pringle DM. Effects of a relationship-enhancing program of care on outcomes. J Nurs Scholarsh 2003; 35:151-6.
86 McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. BMJ 2000; 321:867-71.
87 Miaskowski C, Dodd M, West C, Schumacher K, Paul SM, Tripathy D, Koo P. Randomized clinical trial of the effectiveness of a self-care intervention to improve cancer pain management. J Clin Oncol 2004; 22:1713-20.
88 Mundinger MO, Kane RL, Lenz ER, Totten AM, Tsai WY, Cleary PD, Friedewald WT, Siu AL, Shelanski ML. Primary care outcomes in patients treated by nurse practitioners or physicians: a randomized trial. JAMA 2000; 283:59-68.
89 Murray E, Davis H, Tai SS, Coulter A, Gray A, Haines A. Randomised controlled trial of an interactive mutlimedia decision aid on hormone replacement therapy in primary care. BMJ 2001; 323:1-5.
90 Murray E, Davis H, Tai SS, Coulter A, Gray A, Haines A. Randomised controlled trial of an interactive mutlimedia decision aid on benign prostatic hypertrophy in primary care. BMJ 2001; 323:493-6.
91 Newbury JW, Marley JE, Beilby JJ. A randomised controlled trial of the outcome of health assessment of people aged 75 years and over. Med J Aust 2001; 175: 104-7.

92 Oermann MH. Effects of educational intervention in waiting room on patient satisfaction. J Ambul Care Manage 2003; 26:150-8.
93 Oermann MH, Webb SA, Ashare JA. Outcomes of videotape instruction in clinic waiting area. Orthop Nurs 2003; 22:102-5.
94 Oermann MH, Hamilton J, Shook ML. Using the Web to improve seniors' awareness of their role in preventing medical errors. J Nurs Care Qual 2003; 18: 122-8.
95 Parry C, Coleman EA, Smith JD, Frank J, Kramer AM. The care transitions intervention: a patient-centered approach to ensuring effective transfers between sites of geriatric care. Home Health Care Serv Q 2003; 22:1-17.
96 Penner M, Dicker M, Ens S. Using postcards to increase patient provided information on medication use. Fam Med 1991; 23:44-5.
97 Pugh LC, Tringali RA, Boehmer J, Blaha C, Kruger NR, Capauna TA, et al. Partners in care: a model of collaboration. Holist Nurs Pract 1999; 13:61-5.
98 Radecki SE, Brunton SA. Randomized clinical trial of a diagnostic instrument for pain complaints. Fam Med 1999; 31:713-21.
99 Reavley W, Sorby NGD, Huber JW. Self help programme for anxiety in general practice: controlled trial of an anxiety management booklet. Br J Gen Pract 1991; 41:417-20.
100 Reed J, Weiner R, Cook G. Partnership research with older people - moving towards making the rhetoric a reality. J Clin Nurs 2004; 13:3-10.
101 Reuben DB, Frank JC, Hirsch SH, McGuigan KA, Maly RC. A randomized clinical trial of outpatient comprehensive geriatric assessment coupled with an intervention to increase adherence to recommendations. J Am Geriatr Soc 1999; 47:269-76.
102 Rubenstein LZ, Aronow HU, Schloe M, Steiner A, Alessi CA, Yuhas KE, Gold M, Kemp M, Raube K, Nisenbaum R, et al. A home-based geriatric assessment, follow-up and health promotion program: design, methods, and baseline findings from a 3-year randomized clinical trial. Aging (Milano) 1994; 6:105-20.
103 Sahar J, Courtney M, Edwards H. Improvement of family carers' knowledge, skills and attitudes in caring for older people following the implementation of a Family Carers' Training Program in the community in Indonesia. Int J Nurs Pract 2003; 9:246-54.
104 Saunders SD, Greaney ML, Lees FD, Clark PG. Achieving recruitment goal through community partnerships: the SENIOR project. Fam Community Health 2003; 26:194-202.
105 Schraeder C, Shelton P, Sager M. The effects of a collaborative model of primary care on the mortality and hospital use of community-dwelling older adults. J Gerontol A Biol Sci Med Sci 2001; 56:106-12.
106 Sidani S. Operationalizing self-care within the health care system. Can J Nurs Leadersh 2003; 16:63-5.
107 Sommers LS, Marton KI, Barbaccia JC, Randolph J. Physician, nurse, and social worker collaboration in primary care for chronically ill seniors. Arch Intern Med 2000; 160:1825-33.
108 Stump TE, Dexter PR, Tierney WM, Wolinsky FD. Measuring patient satisfaction with physicians among older and diseased adults in a primary care municipal outpatient setting. An examination of three instruments. Med Care 1995; 33:958-72.

109 Sturgess IK, McElnay JC, Hughes CM, Crealey G. Community pharmacy based provision of pharmaceutical care to older patients. Pharm World Sci 2003; 25: 218-26.
110 Thom DH, Bloch DA, Segal ES. An intervention to increase patients' trust in their physicians. Acad Med 1999; 74:195-8.
111 Thom DH. Training physicians to increase patient trust. J Eval Clin Pract 2000; 6:245-53.
112 Toseland RW, Labrecque MS, Goebel ST, Whitney MH. An evaluation of a group program for spouses of frail elderly veterans. Gerontologist 1992; 32:382-90.
113 Tsay SL, Hung LO. Empowerment of patients with end-stage renal disease - a randomized controlled trial. Int J Nurs Stud 2004; 41:59-65.
114 Von Korff M, Moore JE, Lorig K, Cherkin DC, Saunders K, Gonzalez VM, et al. A randomized trial of a lay person-led self-management group intervention for back pain patients in primary care. Spine 1998; 23:2608-15.
115 Wasson JH, Sauvigne AE, Mogielnicki RP, Frey WG, Sox CH, Gaudette C, Rockwell A. Continuity of outpatient medical care in elderly men. JAMA 1984; 252:2413-7.
116 Wasson JH, Stukel TA, Weiss JE, Hays RD, Jette AM, Nelson EC. A randomized trial of the use of patient self-assessment data to improve community practices. Eff Clin Pract 1999; 2:1-10.
117 Waxman R, Woodburn H, Powell M, Woodburn J, Blackburn S, Helliwell P. FOOTSTEP: a randomized controlled trial investigating the clinical and cost effectiveness of a patient self-management program for basic foot care in the elderly. J Clin Epidemiol 2003; 56:1092-9.
118 Whatley S, Mamdani M, Upshur RE. A randomised comparison of the effect of three patient information leaflet models on older patients' treatment intentions. Br J Gen Pract 2002; 52:483-4.
119 Williams RB, Boles M, Johnson RE. A patient-initiated system for preventive health care. A randomized trial in community-based primary care practices. Arch Fam Med 1998; 7:338-45.
120 Williams JG, Cheung WY, Chetwynd N, Cohen DR, El-Sharkawi S, Finlay I, Lervy B, Longo M, Malinovszky K. Pragmatic randomised trial to evaluate the use of patient held records for the continuing care of patients with cancer. Qual Health Care 2001; 10:159-65.

Is there a need for more patient involvement in European general practice? An intervention study to improve involvement

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7

Abstract

Objective

To implement a programme for involvement of older patients aged 70+ in general practice and to detect quality changes after its implementation.

Methods

The study was performed in 11 European countries as an uncontrolled before-after-study in which a number of GPs and patients answered a questionnaire before and after having received an intervention. The intervention was aimed at motivating, instructing and facilitating GPs and older patients to increase patient involvement during the consultation by use of a specially designed Consultation Leaflet.

Results

Valid data from seven countries exists. Questionnaires were answered and returned by 900 patients and 79 GPs in the pre-intervention phase and 575 patients and 58 GPs after the intervention. In the intervention group 43% of the patients thought that the Consultation Leaflet had improved the consultation and 62% of the GPs found it to be useful. There were no significant differences pre- and post-intervention in patients' perceptions of their level of involvement, their evaluations of consultations and their perceptions of feeling enabled to deal with their health situation.

Discussion

Quality of consultations as measured by patient satisfaction and patient enablement did not improve as a result of the intervention, but nearly half of the patients and two thirds of the GPs found the intervention to be useful. Unselected use of this intervention on all patients cannot be advised. Future studies should focus on the applicability and benefits of the methods for special patient groups.

Introduction

There is room for improvement of older patients' knowledge about their illness and treatment. A quarter do not know about their medical condition[1], and almost a quarter make errors in compliance[2]. It has been shown that patients often do not feel that their GP provides them with sufficient and adequate information, and that they seek additional information elsewhere[3] and often do not voice their true agendas in the consultation[4].

These problems acquire particular urgency among the elderly because they experience more losses of both functions and relations in their network than other patient groups. Furthermore, they have a higher prevalence of diseases and more chronic conditions[5] that require adaptation. They have also learned to be acceptant of authorities because of the historical time in which they grew up, and finally some older people view the process of aging as one that is inevitably linked with disease and therefore they may not contact the doctor[6;7].

Patient involvement, which can be defined as: 'enabling patients to take an active role in deciding about and planning their care', may be a way to overcome these problems[8]. Examples of methods involving patients include: the use of written materials like information leaflets about clinical conditions, the use of questionnaires to seek patients' views on their care or symptoms, teaching of communication skills like those used by the doctor in consultation with patients, or the use of third person (relative, nurse, etc.) to help patients express their preferences. A recent review shows that interventions directed at patients can be successful in increasing patient participation[9]. There is, however, a lack of studies documenting the effects of enhancing patient involvement for older patients on a broad range of outcomes in daily practice.

Methods for involving patients are legion, but only scant information is available on their implementation and their efficiency in everyday general practice, especially for older patients. We therefore set up a study to develop and evaluate an implementation programme aimed at increasing the involvement of older patients in general practice care in western European countries. The focus for this programme was to enable involvement during the consultation process.

The aim of this study was to detect and document changes in the perceived quality of general practice care after implementing a programme for involvement in general practice care of patients aged 70+.

Methods and materials

Design

The study was an uncontrolled before-after-study, in which a number of GPs and a number of patients received an intervention. GPs and patients answered a questionnaire before and after they had received the intervention.

The study was originally performed in eleven countries, but due to procedural differences this paper is based on results from only seven of these countries: Austria, Belgium, England, Germany, Netherlands, Slovenia and Switzerland. The excluded countries are Denmark (made the study as a randomised controlled study without baseline measurement), France (no GP data available), Israel and Portugal (patient data were not linked to GPs).

Intervention

Consistent with theory on implementation and behavioural change, we developed our intervention on the basis of an analysis of barriers for change[10].

The intervention was aimed at motivating, instructing and facilitating GPs and older patients to increase patient involvement during the consultation in general practice care. It was composed of two components. First, the GPs were invited either to attend a two-hour workshop or to receive a 30-minute practice visit, in which they were motivated for patient involvement and instructed in the use of a specific designed Consultation Leaflet, which was the second part of the intervention.

The contents of the workshops and practice visits were: 1) general information on the IMPROVE project; 2) a discussion and exploration of GP's ideas of patient involvement using the SWOT model (Strengths, Weaknesses, Opportunities and Threats); 3) explanation of and instructions in use of the Consultation Leaflet, and 4) practical arrangements on how to include patients, deliver the tool, etc. Depending on practical aspects in each country, it was optional to either send the Consultation Leaflet to patients before their next appointment or to hand it out to them in the waiting room to be filled out before they entered the consultation.

The Consultation Leaflet was designed on the basis of experiences and results from the two former phases of the IMPROVE study; a qualitative study of barriers and facilitators for patient involvement[11] and a programme development study.

The Consultation Leaflet was a small folder with a short motivating text on patient involvement and a mixture of open and pre-structured questions to help patients prepare for the consultation and prioritise which problems they wanted to discuss with their GP.

Participants

GPs

In each country 12 GPs from at least six different practices representing the average GPs were recruited. It was sought to recruit GPs of both sexes, different ages, from different types of practices and from different settings.

Patients

Each GP consecutively recruited 15 older patients aged 70 years and above to answer questionnaires before the GPs had received their intervention. After the intervention each GP again consecutively recruited 15 patients aged 70 and above and asked them to use the Consultation Leaflet and answer a questionnaire after the consultation.

Excluded from the study were mentally disabled patients, patients who were considered to be too sick (e.g. terminally ill) and patients who only came to the consultation for administrative purposes, e.g. for renewal of driver's licence. GPs were asked to keep a record of all patients aged 70+ who came into the practice during the inclusion period by filling out a checklist of whether the patients were offered to be included in the study and if not, reasons should be recorded.

Measures

GPs

Before the intervention the GPs were asked to answer a questionnaire about their experiences with and preferences for patient involvement. The questionnaire was designed specifically for this study on the basis of literature studies and results from the two former phases of the IMPROVE study. At the end of the study, the GPs answered a questionnaire identical to the first one except for the addition of questions concerning their evaluation of the specific intervention.

Patients

Patients included in the pre-intervention phase answered a questionnaire consisting of the Patient Enablement Index (PEI)[12] and selected questions from the COMRADE[13] and the EUROPEP[14], which are all validated questionnaires. Further, the questionnaire contained specific questions about experiences with and preferences for patient involvement. After the intervention, patients in the intervention group answered a questionnaire identical to the questionnaire mentioned above except for the addition of questions concerning their evaluation of the Consultation Leaflet.

Data analysis

Statistical analyses were performed with STATA SE 8.0 and SPSS 10.0 for Windows. Data are expressed as means or as percentages of the total number. Items from questionnaires were dichotomised into positive and negative answers. Differences between the pre-intervention and post-intervention group were assessed for each country separately. Then a common estimate based on the average of all countries' estimates was made. Statistical measures for common estimates of differences between the pre-intervention and post-intervention group could not be calculated due to too large country-specific variations in the material. Analyses at patient level were adjusted for GP clusters. Analyses were adjusted using general linear models with identity link for Bernoulli family, i.e. modelling the risk differences.

Results

From the pre-intervention phase 900 patients and 79 GPs answered and returned the questionnaires, while 575 patients and 58 GPs answered and returned the questionnaires after the intervention, but only patient data that were linked to GPs participating in both the pre- and the post-intervention phased were included. Likewise, we only included GP data from those GPs who had responded both before and after the intervention (Table 1). Response rates and analysis of non-responders could not be obtained since checklists had not been used in all countries. Patients in the intervention group were younger than patients in the pre-intervention group ($p<0.05$), but otherwise no demographic differences where found between the two groups (Table 2). Demographic characteristics of the included GPs are shown in Table 3.

Table 1 Included patients and GPs from the participating countries (absolute numbers)

Country	Patients*			GPs#
	From n GPs	Pre intervention	Post intervention	
Austria	5	46	25	9
Belgium	8	96	73	8
England	7	80	37	2
Germany	13	118	110	13
Netherlands	13	171	121	7
Slovenia	10	141	104	5
Switzerland	14	113	94	5
Total	70	765	564	49

* Only patients from GP practices that participated in both pre-intervention and post-intervention phases were included; # Only GPs who answered both questionnaires were included

Table 2 Patient characteristics

	Pre intervention		Post intervention	
	Valid N		Valid N	
Age	736	77,5 yr (mean)	547	76,5 yr (mean)
Sex	746	37,9 % (male)	549	40,8% (male)
Chronic disease	698	64,3% (yes)	520	64,4% (yes)
Education	737		532	
Primary or lower school		66,2%		65,2%
Secondary school		21,7%		23,2%
Further/higher education		12,1%		11,6%

Table 3 Characteristics of GPs who answered both questionnaires

	Valid N	
Age	47	48,4 yr (mean)
Gender	49	72,8% (male)
Years in practice	46	18,5 yr (mean)
Teacher	48	67,7% (yes)
Practice locality	49	
Solo practice		64,7%
Group practice		7,8%
Partnership practice		27,6%

A comparison of the results from the participating countries showed that small differences between countries did exist but no clear and consistent directional trend could be found. The following results are therefore primarily based on the pooled data from all countries.

Acceptability of Consultation Leaflet

Patients and GPs in the intervention group were asked about their experiences with the Consultation Leaflet. About two thirds (65%) stated they had discussed the Consultation Leaflet during the consultation and 43% thought it made the consultation better. There was some country variation on this matter (Table 4).

Table 4 Patients' experiences with the intervention in each country

Country	Discussed CL during consultation		CL made consultation better*	
	Valid N	% yes	Valid N	% yes
Austria	22	68,2	21	38,1
Belgium	50	52,0	50	30,0
England	26	76,9	28	57,1
Germany	89	69,7	87	49,4
Netherlands	69	52,2	70	24,3
Slovenia	93	75,3	91	58,2
Switzerland	71	62,0	66	42,4
Total	420	65,2	413	42,8

*These numbers refer to those patients who had answered this question, whether or not they had stated that they had discussed the Consultation Leaflet during the consultation.

About three fourths of the GPs found the information and training for patient involvement to be informative (82%) and useful (73%) and one third meant that it had changed their attitudes towards patient involvement. A majority of the GPs also found the Consultation Leaflet easy to use (65%) as well as useful (62%), while fewer thought that the patients found it easy to use (55%) and useful (45%). The number of GPs in each country was too small to detect any country variations.

Changes in preferences for patient involvement

Both before and after the intervention most patients were in favour of the GP involving them in the consultations and no significant changes could be detected except for one question: Relatively fewer patients in the post-intervention group than in the pre-intervention group thought that the GP should let them decide which treatment they should follow (Table 5).

Table 5 Patients' preferences for involvement

	Pre-intervention		Post-intervention		
	Valid N	% pos*	Valid N	% pos*	Δ%
The doctor should discuss available investigations and treatment options with me.	692	98,0	515	98,5	0,5
The doctor should decide which treatment I should have.	681	87,3	510	88,8	1,5
The doctor should let me decide which of the available treatment options I should follow.	630	68,0	467	62,8	-5,2
The doctor should decide in co-operation with me which of the available treatment options I should follow.	691	96,6	492	96,0	-0,6
The doctor should make efforts to know what I think about my condition (e.g. possible causes and treatment).	637	94,3	485	95,6	1,3
The doctor should do his utmost to involve me in his thoughts, plans and decisions about my health.	667	95,6	499	97,5	1,8

* % of patients who agreed or strongly agreed with the listed statements

Like the patients, most of the GPs were in favour of involving patients actively in the consultation; however there was a consistent trend that relatively fewer GPs in the post-intervention group were as strongly in favour of involving patients than in the pre-intervention group (Table 6).

Table 6 GPs' preferences for involvement

	Pre-intervention		Post-intervention		
	Valid N	% pos*	Valid N	% pos*	Δ%
As a doctor I should discuss available investigations and treatment options with my patients.	49	98,0	49	100	2,0
As a doctor I should decide which treatment patients should have.	47	69,6	46	58,7	-10,9
As a doctor I should let the patients decide which of the available treatment options they should follow.	48	43,0	46	57,1	14,1
As a doctor I should decide in co-operation with the patient which of the available treatment options they should follow.	49	98,2	49	100	1,8
As a doctor I should make efforts to attain knowledge of what my patients think about their condition (e.g. possible causes and treatment).	49	100	49	90,5	-9,5
As a doctor I should do my utmost to involve my patients in my thoughts, plans and decisions about their health.	49	74,7	49	87,2	12,6

* GPs who agreed or strongly agreed with the listed statements

Changes in patients' evaluations of consultations

There were no significant differences between patients in the pre-and in the post-intervention group concerning their perceptions of the level of involvement (COMRADE scale in Table 7). Likewise, there were no significant differences between patients in the pre- and the post-intervention group concerning their evaluations of consultations (EUROPEP scale in Table 7) or in their perceptions of feeling enabled to deal with their health situation as a result of their visit to the GP (PEI scale in Table 7).

Table 7 Percentage of patients who gave positive answers on the three validated scales COMRADE*, EUROPEP# and PEI§, pre- and post-intervention.

	Pre-intervention		Post-intervention		
	Valid N	% pos*#§	Valid N	% pos*#§	Δ%
COMRADE					
The doctor gave me the chance to ask for as much information as I needed about the different treatment choices.	621	89,4	480	93,2	3,9*
The doctor gave me the chance to express my opinions about the different treatments available.	592	85,1	445	89,0	3,9*
The information given to me was easy to understand.	688	97,1	510	97,1	0,0
The doctor gave me a chance to be involved in the decisions during the consultation.	603	90,9	447	91,6	0,7
EUROPEP					
The GP made you feel you had time	697	83,7	523	85,3	1,6
The GP showed interest for you	678	85,0	507	86,4	1,4
The GP made it easy to talk about my problems	664	85,9	491	85,5	-0,4
The GP involved me in decisions	623	81,8	437	85,2	3,4
The GP listened carefully	697	87,2	503	89,0	1,8
The GP explained the purpose of treatment	620	86,6	461	88,4	1,8
The GP told me what I wanted to hear	663	82,6	481	87,3	4,8
The GP and I talked about emotional problems	538	79,9	396	77,0	-3,0
Importance of following advice	594	82,2	427	83,5	1,3
Recall from earlier contacts	602	83,7	433	83,3	-0,3
PEI					
Able to cope with life?	637	67,1	460	67,2	0,1
Able to understand your illness?	641	75,8	468	77,0	1,2
Able to cope with your illness?	646	69,7	464	72,1	2,5
Able to keep yourself healthy?	631	69,2	455	72,6	3,4
Confident about your health?	653	64,6	478	64,8	0,2
Able to help yourself?	641	61,4	466	65,2	3,9

*Strongly agree or agree; #Very good or Excellent; §Much better or better

Discussion

No changes in perceived quality of care in general practice consultations were found in this study. The intervention did not entail a rise in the proportion of patients feeling involved during consultations, and patients felt neither more satisfied with the consultations, nor better enabled to deal with their health situation than patients in the pre-intervention group.

These results contradict our initial hypotheses and what has been found in a recent study by Little et al[15], namely that use of a general leaflet increased patient satisfaction, but our results support what has been found in other recent studies: in two randomised controlled clinical trials performed within the past two years, no evidence was found that using different instruments to increase patient involvement had any positive effect on health status[16] or patient satisfaction[17].

There may be several explanations for our outcome: a short workshop or practice visit may be insufficient compared with a longer systematic implementation programme targeting both users and doctors. Further, the intervention was directed at the consultation process which may have disturbed the relationship between patients and GPs, as both parties may have felt that it disturbed the natural flow of the process they were used to. Another study on patients' and GPs' views on using a guidebook for ulcerative colitis found that patients did not use the guidebook because they felt constrained by time limits and they were not actively encouraged by the GPs to use it[18].

Older patients in particular may have had a long and continuous relationship with their GP and they may be more reluctant to accept changes than younger patients. Some of them may have had difficulties seeing the point in using the leaflet and prioritising what they wanted to talk to their doctor about, when all they came for was a control for their hypertension, diabetes or asthma. Further, some patients already habitually write a note for the GP, and therefore it would make no difference in the consultation whether they used a 'home-made' note or the pre-structured note/leaflet from the GP.

It may also be that patient involvement already is at its optimal level. Patients did, indeed, feel involved to a large degree in our study and there may actually be very little room for increasing their involvement. That is, patients are being involved as much as they want to and are capable of. It should also be taken into consideration that not all patients are capable of being involved and not all patients may want to be involved[8].

The still increasing interest in the doctor-patient relationship, the communicative aspects of the consultation process and the decision-making process has delegated more responsibility to patients and has introduced an almost paradigmatic shift away from a paternalistic model of the doctor-patient relationship towards a more dialogue- or patient-centred model. There may, however, be a limit to how much influence patients actually want on the consultation process and on the decision-making process in the consultation. The GP-patient relationship is a priori a legal, unequal relationship. The patient seeks help from the GP, who by virtue of his/her profession is expected to be in a position to help patients deal with their discomforting symptoms. When GPs try to involve patients and make them participate in decisions, patients may feel confused and left with unmet expectations instead of feeling helped. Even though some patients may want to be involved and participate in the decision-making process, they may still want the doctor to be authoritative as opposed to authoritarian.

This study suffers from the weakness that it is a before-after study and from the fact that there was much variation between countries in sampling procedures and organisation of general practice. The cultural variation between countries presents a large risk for introducing uncontrolled biases and confounders into the results. Further, the patient questionnaire we used may not have been good enough at capturing the effects of the intervention.

The strength of the study, however, is that because of the participation of many countries, we have data from relatively many patients and despite some country variation, no systematic differences between countries could be found. This leads us to assume that our results are valid and generalisable.

Conclusion

The results from this study do not support the systematic use of this kind of intervention. Patients did not experience consultations as better, nor did they feel better helped. Using formal methods for improving patient involvement may hence be counterproductive, and further studies should focus on the possible applicability and benefits of the methods for special patient groups. Alternatively other methods should be explored that can be applied outside the consultation setting.

References

1 Radhamanohar M, Than M, Rizvi S. Assessment of patients' knowledge about their illness and treatment. Br J Clin Pract 1993; 47:23-5.

2 Blenkiron P. The elderly and their medication: understanding and compliance in a family practice. Postgrad Med J 1996; 72:671-6.

3 Coulter A, Entwistle V, Gilbert D. Informing Patients. An assessment of the quality of patient information materials. London: King's Fund, 1998.

4 Barry CA, Bradley CP, Britten N, Stevenson FA, Barber N. Patients' unvoiced agendas in general practice consultations: qualitative study. BMJ 2000; 320:1246-50.

5 Wolff JL, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. Arch Intern Med 2002; 162:2269-76.

6 Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. Br J Gen Pract 1997; 47:427-30.

7 Foster J, Dale J, Jessopp L. A qualitative study of older people's views of out-of-hours services. Br J Gen Pract 2001; 51:719-23.

8 Wensing M, Baker R. Patient involvement in general practice care: a pragmatic framework. Eur J Gen Pract 2003; 9:62-5.

9 Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns 2004; 52:7-16.

10 Grol R, Grimshaw J. From best evidence to best practice: effective implementation of change in patients' care. Lancet 2003; 362:1225-30.

11 Wetzels R, Geest TA, Wensing M, Ferreira P, Grol R, Baker R. GPs' views on involvement of older patients: A European qualitative study. Patient Educ Couns 2004; 53:183-8.

12 Howie JG, Heaney DJ, Maxwell M, Walker JJ. A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. Fam Pract 1998; 15:165-71.

13 Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M, et al. The development of COMRADE-a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns 2003; 50:311-22.

14 Grol R, Wensing M, Mainz J, Jung HP, Ferreira P, Hearnshaw H, et al. Patients in Europe evaluate general practice care: an international comparison. Br J Gen Pract 2000; 50:882-7.

15 Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J, et al. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ 2004; 328:441.

16 Kennedy AD, Sculpher MJ, Coulter A, Dwyer N, Rees M, Abrams KR, et al. Effects of decision aids for menorrhagia on treatment choices, health outcomes, and costs: a randomized controlled trial. JAMA 2002; 288:2701-8.

17 Cornbleet MA, Campbell P, Murray S, Stevenson M, Bond S. Patient-held records in cancer and palliative care: a randomized, prospective trial. Palliat Med 2002; 16:205-12.

18 Oxford Textbook of Primary Medical Care Volume 1: Principles and Concepts. New York: Oxford University Press, 2004.

A consultation leaflet to improve an older patient's involvement in general practice care: a randomised trial

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Health Expectations, in press

8

Abstract

Objective

To evaluate the effects of a programme to enhance the involvement of older patients in their consultations in general practice.

Design

Cluster randomised trial, in which data was collected from different cohorts.

Setting and participants

25 General practices in the Southeast part of the Netherlands and their patients aged 70 years and over.

Intervention

Patients in the intervention group received a leaflet to help them prepare for the consultation. GPs received an outreach visit to optimise older patients' involvement when visiting their GP. Patients in the control group received usual care.

Main outcome measures

Questionnaires measuring involvement (COMRADE), enablement (Patient Enablement Index) and satisfaction with their care (EUROPEP).

Results

Pre-intervention 315 patients and post-intervention 263 patients were included. Subjects were satisfied with their involvement and the GP's behaviour during the consultation. No differences in effect as a result of the leaflet on involvement, enablement or satisfaction were found between the intervention and the control group. Of 318 patients who received the leaflet and visited their GP in the intervention period, 47 patients used the leaflet. These users were more accustomed to prepare themselves for consultations. Users reported more psychological problems than non-users.

Discussion

No relevant effects of the implementation programme on involvement, enablement or satisfaction were found. Other strategies are needed to enhance involvement of older patients in their care. Alternatively, older patients may perceive themselves sufficiently involved.

Introduction

Involving patients actively in their care may have a positive influence on patients' health outcomes, their adherence to treatments, their functional independence[1-3] and their satisfaction with care[4;5]. Involving patients in their care is obviously important to meet their health needs. The mutuality that originates from involvement is an achievement of both patients and doctors, and requires the active participation of patients in decisions regarding their care and situations[6]. Although patient satisfaction with care is usually very high, it has been suggested that patients' involvement in their care needs to be improved. There is a wide range of methods for enhancing the involvement of patients[7], but only scant information is available on their implementation in everyday general practice, especially for older patients.

A recent review showed that interventions directed at patients can be successful in increasing patient participation[8]. As far as written materials are concerned, a general leaflet that encouraged patients to raise concerns during their GP visit improved patients' satisfaction and perceived communication[9]. Another study found an increase in consultation length and more question asking as a result of a leaflet designed to increase the level of patient participation in consultations[10]. So there is some evidence on the positive influence of written patient directed interventions, but it is not clear whether they are suitable for older patients as well[11]. In one of the above-mentioned studies younger patients were more likely to benefit from the intervention than older patients. It was suggested that older patients have a more fixed pattern of consultations and a high level of satisfaction with care, so they may have less need to modify their behaviour in consultations[10].

In an unpublished pilot study we evaluated four different written patient involvement tools. This pilot showed that such tools are definitely useful for some older patients in some situations. The tools helped to explore patients' ideas, fears and expectations and stimulated older patients to address important issues that they had not addressed before. But, GPs and patients need support, encouragement and time to use such tools if they are to enhance their involvement.

We developed and tested a consultation leaflet implementation programme, in which GPs and older patients were stimulated to optimise older patients' involvement when visiting their GP.

Beforehand we hypothesised that:

- Implementation of the consultation leaflet would improve patients' evaluations of their care;
- patients with underreported health problems would benefit from the intervention because they would be more likely to discuss these[12].

The aim of the study was to determine the effects of the programme and to test these hypotheses.

Methods

A cluster-randomised trial was performed in which the pre-/post-intervention data was collected from different cohorts (Figure 1). This design was chosen because we could not predict when patients included in the baseline measurement were going to visit their GP again and we had a limited study time. The Ethical Committee of the University Medical Centre Nijmegen assessed the study and gave approval.

Randomisation

We recruited 25 GPs in the Southeast of the Netherlands. Recruitment of GPs occurred in May and June 2002 by mail. GPs were randomised. To ensure similar numbers of GPs in each group we used block-randomisation (blocks of two). This random group allocation of GPs was performed after the baseline measurement among patients. To secure blinding of allocation, practices were numbered in the order of their arrival in our mail. All participating GPs in a particular practice were randomised to the same intervention. An independent person, who was blinded for the practices as these were numbered, performed the allocation.

Participants

For the baseline measurement the participating GPs were asked to send a letter with a questionnaire to 25 patients aged 70 years or older who had consulted them recently. Study subjects were patients aged 70 years or over, consulting one of the included general practices during the study period (June – November 2002). Patients were excluded if they were visually impaired or if their GP thought they were not suitable for participating.

Post intervention GPs were asked to send questionnaires to the last 30 patients (aged 70 or over) who visited them. Due to difficulties with organisation of

patient appointments in some practices it was not always possible to gather the needed 30 patients per GP.

Sample size calculation

To detect a medium effect (effect size=0.5)[13] between intervention and control group we required 24 general practitioners and 10 patients per GP (power=0.80, alpha=0.05, intra-cluster correlation=0.1)[14]. A formula was used to calculate a sample size for cluster randomised studies[15]. To account for non-response we asked GPs to invite 25 patients to participate. Since pre-intervention response rates were low, post intervention GPs were asked to send questionnaires to the last 30 patients (aged 70 or over) who visited them.

Intervention

All patients aged 70 or over in the intervention practices received a consultation leaflet by mail. The leaflet consisted of a short motivating text on patient involvement and a mixture of open and pre-structured questions to help patients prepare for the next consultation and prioritise which problems they wanted to discuss with their GP (Box 1). The leaflet was based on questions from the instruments used in the pilot study. These questions were selected as they helped to explore patients' ideas, fears and expectations and stimulated them to address important issues.

Box 1 Content of consultation leaflet

Two general open questions:
- Which points do I want to raise with the doctor?
- What thoughts or ideas do I have about these points, for example causes, possible treatments?
- What do I want the doctor to do? (Five questions to be answered with yes or no: 1. Investigate, 2. Explain causes/diseases, 3. Prescribe medication, 4. Give advice on what I can do myself, 5. Other (please say what it is))

Three questions to be answered on a 5-point scale*:
- In general, would you say your health is:
- During the past 2 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities?
- To what degree do you feel lonely?

* (poor to excellent); Derived from Dartmouth COOP Functional Assessment Charts/WONCA. ©Trustees of Dartmouth/COOP project 1985

We concluded from our previous qualitative study that it is important to include GPs in the implementation of the patient involvement leaflet as well[16].

Therefore GPs in the intervention group received a 30-minute practice visit, in which they were motivated for involving patients and instructed in the use of the consultation leaflet. We used the SWOT (strengths, weaknesses, opportunities and threats) model to help the GP consider all aspects of involvement. In this visit we used and informed the GPs about the findings of previous qualitative studies performed among GPs and patients[16].

GPs and their patients in the control group did not receive any intervention or information; their usual care was continued.

Outcome measures

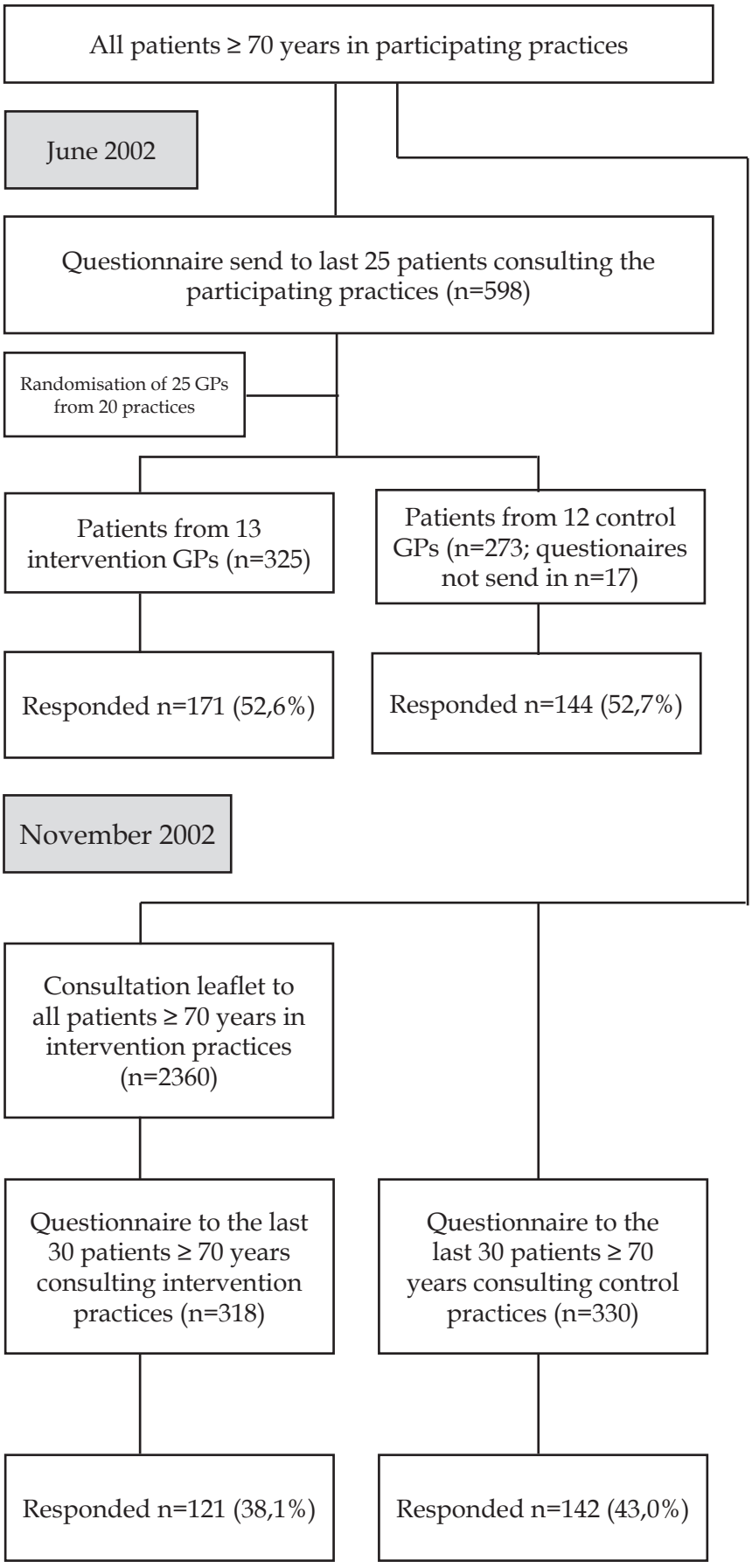
The primary outcome measure was the use of the leaflet and perceived involvement in primary care, measured using a questionnaire. We used four questions from the COMRADE[17] 'Satisfaction with communication'-scale, scored on a 4-point scale (strongly agree to strongly disagree); six questions from the Patient Enablement Index (PEI)[18], scored on a 3-point scale (much better, better, same or less); and ten questions from EUROPEP[19], scored on a 5-point scale (poor to excellent). In addition, we measured patient reported use of the leaflet, consultation length, and demographic characteristics and whether they discussed one of eight underreported health problems (visual, hearing, urinary, sleeping, or memory problems, loneliness, depressive or other mental symptoms).

The questionnaires at baseline and post-intervention were similar, except for some process evaluation questions about the consultation leaflet after the intervention period.

Analysis

An intention to treat analysis at the patient level was performed using SPSS 11.0 en SAS (8.0) software. Mean scores per scale (PEI, COMRADE, EUROPEP) and consultation time were calculated. Missing values were substituted for mean scores only if two-third of the scale-items were completed. We used a multi-level model to compare the estimated effect sizes of intervention and control group per outcome measure. The model included a correction for GP clustering. The multi-level analysis thus showed whether the estimated effect size differences (between intervention and control group) were statistically significant. The same analysis was performed on patients who reported using the intervention leaflet as intended. Differences in demographic characteristics and underreported health problems were calculated using a chi-square test.

Figure 1 Flow chart patients



Results

Recruitment and response rates

After randomisation the sample consisted of 13 GPs from 11 intervention practices and 12 GPs from 9 control practices. Pre-intervention 315/598 (52,6%) patients returned their questionnaire, post-intervention, 263/648 (41%) patients returned their questionnaire (Figure 1). Patient characteristics pre- and post-intervention are presented in Tables 1 and 2. Post-intervention there were significantly more females in the intervention group (chi-square: 6,89 (df 1); p=0.009) (Table 2).

Table 1 Baseline characteristics of study population; n (%)

	Intervention group (n=171)	Control group (n=144)
Gender		
Male	63 (36,8%)	68 (47,2%)
Female	107 (62,6%)	76 (52,8%)
Age (mean ± sd)	75.6 ± 4.6	75.6 ± 4.7
<80 year	131 (76,6%)	110 (76,4%)
≥80 year	39 (22,8%)	34 (23,6%)
Education		
Primary or lower secondary school	105 (61,4%)	83 (57,6%)
Upper secondary school	48 (28,1%)	39 (27,1%)
Further and higher education	17 (9,9%)	15 (10,4%)
Health		
Excellent	2 (1,2%)	6 (4,2%)
Very good	15 (8,8%)	9 (6,3%)
Good	63 (36,8%)	50 (34,7%)
Fair	84 (49,1%)	71 (49,3%)
Poor	5 (2,9%)	6 (4,2%)
Serious or chronic diseases		
Yes	99 (57,9%)	66 (45,8%)
No	67 (39,2%)	72 (50,0%)

Table 2 Post intervention characteristics of study population; n (%)

	Intervention group (n=121)	Intervention group non-users (n=74)	Intervention group users (n=47)	Control group (n=142)
Gender				
Male	46 (38,0%)	32 (43,2%)	14 (29,8%)	77 (54,2%)
Female	74 (61,2%)	41 (55,4%)	33 (70,2%)	64 (45,1%)
Age (mean ± sd)	76,2 ± 4,8	76,3 ± 4,9	75,9 ± 4,7	75,2 ± 4,8
<80 year	95 (78,5%)	57 (78,1%)	38 (80,9%)	109 (76,8%)
≥80 year	25 (20,7%)	16 (21,6%)	9 (19,1%)	32 (22,5%)
Education				
Primary or lower secondary school	68 (56,2%)	44 (59,5%)	24 (51,1)	85 (59,9%)
Upper secondary school	39 (32,2%)	22 (29,7%)	17 (36,2)	44 (31,0%)
Further and higher education	10 (8,3%)	6 (8,1%)	4 (8,5%)	12 (8,5%)
Health				
Excellent	3 (2,5%)	2 (2,7%)	1 (2,1%)	0
Very good	10 (8,3%)	7 (9,5%)	3 (6,4%)	10 (7,0%)
Good	38 (31,4%)	24 (32,4%)	14 (29,8%)	59 (41,5%)
Fair	59 (48,8%)	34 (45,9%)	25 (53,2%)	66 (46,5%)
Poor	4 (3,3%)	2 (2,7%)	2 (4,3%)	6 (4,2%)
Serious or chronic diseases				
Yes	59 (48,8%)	33 (44,6%)	26 (55,3%)	66 (46,5%)
No	56 (46,3%)	37 (50%)	19 (40,4%)	74 (52,1%)

Effect of intervention

Concerning their involvement, patients were satisfied with the information they were given, their opportunities to ask questions, to give their opinion and to take part in decisions. No differences between intervention and control group were detected. Concerning enablement, patients felt themselves the same or better enabled to deal with their health problem after the consultation. However, the intention to treat analysis showed significant negative results in these scores (Table 3). Intervention patients seemed to be less able to cope with their health problem after visiting their doctor compared to control patients.

Table 3 Mean scores per independent variable per group, estimated effect size differences and p-value of multi-level analysis

	Intervention group (n=121)		Intervention group who used leaflet correctly (n=47)	Control group (n=142)		Estimated Effect size difference[*1] (95% CI)[#]	p-value	Estimated Effect size difference[*2] (95% CI)[#]	p-value
	Pre	Post	Post	Pre	Post				
PEI (range 0-2)	0,72	0,56	0,56	0,62	0,69	-0,232 (-0,444/-0,021)	0.032	-0,226 (-0,475/0,022)	0.075
COMRADE (range 1-4)	1,82	1,83	1,83	1,89	1,80	0,090 (-0,096/0,277)	0.344	0,091 (-0,129/0,311)	0.42
EUROPEP (range 1-5)	4,19	4,32	4,20	4,18	4,37	-0,056 (-0,302/0,192)	0.660	-0,171 (-0,472/0,131)	0.267
Consultation length (min.)	13,0	12,2	13,0	12,5	12,2	-0,545 (-2,513/1,423)	0.588	0,411 (-2,043/2,866)	0.74

[*1] Difference in estimated effect between control and intervention group, corrected for clustering;

[*2] Difference in estimated effect between control and intervention group who used leaflet correctly, corrected for clustering;

[#] Calculated as +/- (1,96*Standard Error)

Finally, patients were very satisfied with the way their GP behaved during the consultation. No differences between intervention and control group were detected.

Table 4 Percentage of older patients that discussed one of eight known underreported health problems*

	Intervention group (n=121)	Intervention group		Chi square Users versus non-users	Control group (n=142)	Chi square Control versus intervention
		Non-users (n=74)	Users (n=47)	p-value		p-value
Visual problems	13/98 (13,3%)	8/60 (13,3%)	5/38 (13,2%)	0.980	22/113 (19,5%)	0.227
Hearing problems	13/96 (13,5%)	11/59 (18,6%)	2/37 (5,4%)	0.065	19/108 (17,6%)	0.427
Urinary problems	20/99 (20,2%)	13/61 (21,3%)	7/38 (18,4%)	0.728	21/104 (20,2%)	0.999
Sleeping problems	19/96 (19,8%)	12/60 (20,0%)	7/36 (19,4%)	0.947	21/110 (19,1%)	0.899
Memory problems	10/91 (11,0%)	6/55 (10,9%)	4/36 (11,1%)	0.976	7/99 (7,1%)	0.345
Loneliness	14/93 (15,1%)	7/56 (12,5%)	7/37 (18,9%)	0.397	9/102 (8,8%)	0.178
Depressive symptoms	14/93 (15,1%)	6/57 (10,5%)	8/36 (22,2%)	0.124	14/104 (13,5%)	0.749
Other mental symptoms	15/88 (17,0%)	5/51 (9,8%)	10/37 (27,0%)	0.034	9/102 (8,8%)	0.089

* Scores are not corrected for clustering

Use of leaflet

Of 318 patients who received the leaflet and visited their GP in the intervention period, 47 patients either used the leaflet at home (n=39) and/or during the consultation (n=26) and/or they discussed the points they had written down (n=36). Sub-analyses showed that the scores for these 47 patients did not differ significantly on the outcome measures from those of the control group or the intervention group non-users (Table 3). Intervention group leaflet users reported more psychological symptoms to their GP compared with non-users

of the leaflet (p=0.034). No other differences in discussion of underreported health problems were found (Table 4). The demographic characteristics of the leaflet users were not significantly different to those of the non-users, although there were more females among the users. The prevalence of chronic diseases was similar. However, users were more accustomed to prepare themselves for the consultation than non-users. Roughly one third of non-users (25/74) and almost two-third of users (28/47) said they prepared themselves for consultations (chi square: 11,5 (df 2); p=0.003).

Discussion

Our study showed no relevant effect of the implementation programme on involvement, enablement or satisfaction of older patients in their general practice care. Patients, who were not used to preparing themselves, did not change this habit. The intervention may have had a negative effect on those who received the leaflet, but did not use it. Patients were not stimulated to discuss more health problems, apart from mental health problems. Finally, we could not identify a subgroup of patients in which the programme was effective.

Another intervention trial to empower older patients during a group programme with cue cards and a preparation booklet for consultations also did not show any significant differences[5]. Although, the sub-group analysis among programme attenders in that study did show more active behaviour among intervention patients.

There may be several reasons for these disappointing results. One reason may be the heterogeneity of the group of older patients, who varied in the conditions they had, in their attribution of clinically important changes to aging, in educational background and in the patient role they adopted. Patients may need personally tailored interventions to become more involved instead of a fixed programme.

Another reason may be consulting style adopted by older patients. Most had illnesses which resulted in frequent GP consultations. Together with their high satisfaction with care, older patients may need longer-term personal support to modify their consulting behaviour. For example, two intervention studies among older adults that evaluated a pre-consultation interview on the number of raised problems during consultations showed a trend towards more raised problems[20] and question-asking[21].

Another reason could be that older patients already perceive themselves to be sufficiently involved. A qualitative study has suggested that older patients have some worries about becoming more involved, but also positive expectations of enhanced involvement[22].

Finally, the fact that we did not find any relevant differences might be related to some limitations of our study. First of all, the post intervention response was low. There is no clear reason for this, except for the fact that this measurement took place in December, a month of celebration. Secondly, there were many missing values, suggesting that the questionnaire might have been too difficult for our study participants. Thirdly, ideally we would have chosen a design in which pre- and post-intervention patients were the same. However, as mentioned this was not possible for practical reasons. We think however, that our design was second best, as it rules out the time effect and there were no major differences between the different groups, except for the overrepresentation of male patients in the post-intervention control group. Finally, a questionnaire may not be the appropriate measure for involvement.

Our study and previous studies suggest that it is difficult to improve older patients' involvement in their care. It seems that written materials alone, whether or not offered by an involvement-focused GP, are not effective and that older patients may need to be assisted in using them. Face-to-face communication may be more appropriate, for example shortly before the consultation. These kinds of consultation preparations have been tried before, for example in cancer research[23], where they seemed effective.

It was not clear which group of older patients might benefit from an intervention to enhance their involvement. Maybe general interventions to improve involvement are too vague, or too abstract for older patients, and therefore focusing on more concrete, disease specific interventions might be more successful to improve older patients' involvement. The above-mentioned interventions in cancer research to improve patient participation are good examples of disease specific interventions[24;25]. Further research should focus on subgroups of older patients, in combination with face-to-face interventions that stimulate involvement.

References

1 Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med Care 1989; 27:S110-S27.

2 Rodin J. Aging and health: effects of the sense of control. Science 1986; 233:1271-6.

3 Roter DL, Hall JA, Merisca R, Nordstrom B, Cretin D, Svarstad B. Effectiveness of interventions to improve patient compliance: a meta-analysis. Med Care 1998; 36:1138-61.

4 Lewis JR. Patient views on quality care in general practice: Literature review. Soc Sci Med 1994; 39:655-70.

5 Tennstedt SL. Empowering older patients to communicate more effectively in the medical encounter. Clin Geriatr Med 2000; 16:61-70, IX.

6 Gafaranga J, Britten N. "Fire away": the opening sequence in general practice consultations. Fam Pract 2003; 20:242-7.

7 Wensing M, Grol R. What can patients do to improve health care? Health Expect 1998; 1:37-49.

8 Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns 2004; 52:7-16.

9 Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J, Kendrick T. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ 2004; 328:441.

10 McCann S, Weinman J. Empowering the patient in the consultation: a pilot study. Patient Educ Couns 1996; 27:227-34.

11 McCormick WC, Inui TS, Roter DL. Interventions in physician-elderly patient interactions. Res Aging 1996; 18:103-36.

12 Wetzels R, van Eijken M, van Weel C, Grol R, Wensing M. Self-management is not related to reduced demand for primary care in independent living elderly. J Am Geriatr Soc 2005; 53:918-9.

13 Cohen J. A Power Primer. Psychol Bull 1992; 112:155-9.

14 Campbell M, Grimshaw J, Steen N. Sample size calculations for cluster randomised trials. Changing Professional Practice in Europe Group (EU BIOMED II Concerted Action). J Health Serv Res Policy 2000; 5:12-6.

15 Campbell MK, Thomson S, Ramsay CR, MacLennan GS, Grimshaw JM. Sample size calculator for cluster randomized trials. Comput Biol Med 2004; 34:113-25.

16 Wetzels R, Geest TA, Wensing M, Ferreira PL, Grol R, Baker R. GPs' views on involvement of older patients: an European qualitative study. Patient Educ Couns 2004; 53:183-8.

17 Edwards A, Elwyn G, Hood K, Robling M, Atwell C, Holmes-Rovner M, Kinnersley P, Houston H, Russell I. The development of COMRADE--a patient-based outcome measure to evaluate the effectiveness of risk communication and treatment decision making in consultations. Patient Educ Couns 2003; 50: 311-22.

18 Howie JG, Heaney DJ, Maxwell M, Walker JJ. A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. Fam Pract 1998; 15:165-71.

19 Grol R, Wensing M, Mainz J, Jung HP, Ferreira P, Hearnshaw H, et al. Patients in Europe evaluate general practice care: an international comparison. Br J Gen Pract 2000; 50:882-7.
20 Rost K, Frankel R. The introduction of the older patient's problems in the medical visit. J Aging Health 1993; 5:387-401.
21 Kimberlin C, Assa M, Rubin D, Zaenger P. Questions elderly patients have about on-going therapy: a pilot study to assist in communication with physicians. Pharm World Sci 2001; 23:237-41.
22 Wetzels R, Wensing M, van Weel C, Grol R. Ouderen over hun rol in het huisartsenconsult. Een kwalitatieve interviewstudie. (Older patients about their role in general practice consultations. A qualitative study). TSG 2005; 83:93-7.
23 Sepucha KR, Belkora JK, Mutchnick S, Esserman LJ. Consultation planning to help breast cancer patients prepare for medical consultations: effect on communication and satisfaction for patients and physicians. J Clin Oncol 2002; 20:2695-700.
24 Butow PN, Dunn SM, Tattersall MH, Jones QJ. Patient participation in the cancer consultation: evaluation of a question prompt sheet. Ann Oncol 1994; 5: 199-204.
25 Brown R, Butow PN, Boyer MJ, Tattersall MH. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. Br J Cancer 1999; 80:242-8.

Self-management to improve functional status and mobility in older osteoarthritis patients: a randomised trial in general practice

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Submitted

9

Abstract

Background

Osteoarthritis (OA) is a highly prevalent disease in an aging population, and has an impact on patients' functional status. For mild OA symptoms life-style improvements are beneficial. Self-management contributes to better health status and it is a challenge to implement effective methods to improve self-management in OA patients in general practice. We evaluated a nurse-based intervention of minimal intensity on older patients' self-management with the aim to assess its effects on mobility and functioning.

Design

Randomised controlled trial of patients (≥ 65 years) with hip or knee osteoarthritis from nine general practices in the Netherlands.

Outcomes

Patients' mobility using the Timed Up and Go test (TUG) and patient reported functioning using an osteoarthritis specific scale (Dutch AIMS2 SF).

Results

Fifty-one patients were randomised to the intervention group and 53 to the control group. Functioning improved in the intervention group compared to the control group (p=0.04), while mobility did not change. There were no differences between the groups regarding consultations with GPs or physiotherapists, or medication use.

Discussion

A nurse-based intervention of minimal intensity of older patients' self-management led to better functional status, without increased use of health care resources.

Introduction

In an aging population arthritis is one of the most common diseases with an impact on patients' functioning and on primary care. World-wide estimates are that 9,6% of men and 18% of women aged ≥ 60 years have symptomatic osteoarthritis (OA). OA leads to high disease burden and accounts for many years of living with a disability[1]. There are beneficial treatments for OA, in end-stage OA joint replacement may be necessary, but in mild OA management is usually focused on improving life-style, by education on self-management[2-5], weight loss[6], physical exercise[7-11] and rational use of painkillers. These advices have the potential to improve patients' pain, self-reported physical function, mental well being and they may have positive effects on their depressive symptoms and fear. However, one of these treatments, the "coxibs", were recently compromised, because of their cardiovascular risk[12]. This highlights the risks of treatment of an in itself not lifethreatening condition like OA and emphasises the danger of medicalisation and therefore this pleads for non-medication interventions. Guided self-management can help patients steering a middle course between solving OA symptoms themselves and consulting a GP and protect against overreliance on painkillers.

However, most self-management and life-style programmes are extensive in time and money as they include several sessions with for example physiotherapists, nurses and other OA patients[13]. Our aim was to design an intervention of minimal intensity yet still effective, in order to promote implementation in daily practice. From previous research we know that providing written material alone is not effective[14], as behaviour changes in older patients need more personal face-to-face education. In the Netherlands general practices more and more co-operate with practice nurses. It seemed therefore feasible to design an intervention with such a nurse who educates older patients on their self-management with OA symptoms. By using goal-setting theory[15] the intervention aimed to improve exercise, use of a walking aid, and some weight-loss when appropriate. We hypothesised that improved self-management leads to improved health outcome.

We evaluated this nurse-based intervention to improve older OA patients' self-management, with the aim to assess its impact on their mobility and functioning.

Methods

Study Population/Recruitment

We performed a patient randomised controlled trial between April 2004 and January 2005. The ethical committee of the Radboud University Medical Centre Nijmegen gave approval for the study. The trial was based on the practice populations of nine practices in the Eastern region of the Netherlands.

Participants

Seventeen GPs from nine practices recruited patients with OA of the hip or knee from their practice medical records. These patients were included if they complied with the following inclusion criteria: aged 65 years or older and ICPC-code L89 (OA of the knee) or L90 (OA of the hip) or diagnosis osteoarthritis of the hip and/or knee in patient's practice medical history record. Patients were excluded if they had undergone a hip or knee replacement operation, or had been referred for it or when their GP thought they were not suitable for participating (for example because of severe psychosocial circumstances, or a terminal disease). An informed consent letter was sent by the GP and patients were included after they had replied positively.

Intervention

We designed a nurse-based intervention based on previous more extensive programmes and based on our findings in previous studies. The intervention consisted of education on self-management of OA symptoms by a nurse and aimed to improve mobility and physical functioning. Patients were educated to use symptom registration to get insight in own symptoms and subsequently they were taught goal setting for improving these symptoms. This education took place in a home-visit with a follow-up phonecall by a nurse. During this visit the nurse educated the patients on the items of physical exercise, weight loss, use of a walking aid and how to use over the counter medication. Patients discussed with the nurse one of the items they wanted to improve, and subsequently the patients set a goal in improving this item. Patients were given an educational leaflet about osteoarthritis (developed by the Dutch College of General Practitioners) and a booklet with health-status charts. Both were given to improve patients' self-management of their OA symptoms. The health-status charts were based on the Wonca COOP-charts[16]. On these charts the patients registered their level of exercise, pain-level and their impairments during a 2-month period. Aim of these charts was to give patients insight in

their level of functioning and therefore to be able to set new goals to improve an area in which their functioning was not yet optimal. The osteoarthritis-leaflet and health-status charts were sent by mail approximately one week before a nurse visited the patients. The charts were sent with the request to fill in the first part and discuss this during a 30-minute home visit. After approximately 3 months the nurse contacted the patients by means of a follow-up phonecall. The second part of the health-status charts were then discussed as well as the progressing towards the goal(s) set. The nurse had undergone a certified education in rheumatology. Patients in the control group received only the educational leaflet about osteoarthritis.

Outcome measures

Primary outcome measurements were the Dutch version AIMS2 SF[17] and the Timed Up and Go test (TUG)[18]. The Dutch-AIMS2 SF is an arthritis specific health status scale and consisted of the following subscales: physical functioning, pain, social functioning and mood symptoms, all scored on a 5-point scale. The TUG is an objective outcome measure for mobility in older patients. Secondary outcome measures were patient-reported number of contacts with the GP and physiotherapist and whether they used medication or not.

Pre- and post-intervention data were obtained in two ways. A patient questionnaire was used to collect all patient reported outcomes. The TUG was performed by the nurse in the intervention group and by a research assistant in the control group for the pre-intervention data. A research assistant measured in all patients the post-intervention TUG, he was blinded for intervention-control condition.

Randomisation

An independent statistician made randomisation lists in advance for each practice. To ensure similar numbers of patients from different practices in each group, block-randomisation (blocks of two) was used. These randomisation lists were represented in nine different spreadsheets. Every patient who entered the study was given a number that represented the order of entrance in the study for that practice. Subsequently, the number of entrance per practice in the spreadsheet was used to randomly assign the patient to intervention or control group.

Sample size calculation

To estimate sample size, a power calculation was performed using the subscale lower body limitations of the Dutch AIMS SF (Arthritis Impact Measurement Scales Short Form)[17;19] and the Timed Up and Go test[20]. We wanted to detect a small to medium effect (Mean Standardised Difference of 0.4), with alpha 0.05 and beta 0.20. We needed to include 49 patients per group[21]. Anticipating on refusal rates and loss to follow-up we approached 158 patients.

Analysis

In the analysis follow-up scores of patients were adjusted for baseline scores[22]. Independent variables were therefore randomisation (intervention or control group) and the baseline scores of the respective dependent variables. We used an intention-to-treat analysis. The analyses were performed using SPSS (version 12) software. Data were checked for normality of residuals. For the primary outcome measure Timed Up and Go test we used a logistic regression technique. TUG times were divided into two clinically relevant groups (≤12 and >12 seconds) on the basis of literature[23]. Dutch AIMS SF scales (sumscale and different subscales) were analysed with a linear regression technique. The secondary outcome measures GP visits, physiotherapist visits were analysed using a chi-square test. We did not substitute missing values in any of the scales.

Results

A total of 158 patients were sent an informed consent letter and a questionnaire. After one reminder 125 patients (79,1%) responded. Of these 104 patients were included and randomly assigned (Figure 1). Fifty-one patients were allocated to the intervention group and 53 were allocated to the control group. Fifty-four patients (of the initial 158) could not be included: 33 did not respond to the study invitation, 7 forgot to fill in their names, 12 did not give informed consent, 1 moved to another region and 1 died. Those excluded were not significantly different in age and gender compared to participants. At baseline no differences in self-reported characteristics between intervention and control group patients were detected (Table 1). Due to several reasons nine patients withdrew their participation during the study (motivation problems, moved elsewhere, hip/knee surgery, too severe problems of co-morbidity and treatment by a geriatric specialist) (Figure 1). Main results are described below and schematically presented in Table 2.

AIMS2-SF

When considering patients' self-reported functioning, intervention patients improved 4,5 points on the AIMS2-SF sum score (from 49,75 to 45,26), compared to 0,12 points for control patients (from 47,04 to 46,92) (p=0,04). This is a 9% relative improvement in overall functioning for intervention patients. When the different subscales were considered individually, none had a significant improvement compared to the control group. However, intervention patients improved on all subscales while in the control group the before-after measurements went merely in the different direction.

Timed Up and Go test

With respect to the Timed Up and Go test the shift towards the group ≤12 seconds in the intervention group was more or less equal to the shift in the control group. One third of the intervention patients performed the TUG below 12 seconds at baseline and half of the patients after the intervention. For the control group this was 41% and 54% respectively (Table 2).

Table 1 Patient reported characteristics of included patients (n=104)

Characteristic	Intervention N=51 %	n	Control N=53 %	n	t/Mann Whitney	Chi²	p-value
Gender							
F	76,5	39	75,5	40			
M	23,5	12	24,5	13		0.014	0.905
Type of osteoarthritis							
Knee	52,9	27	54,7	29			
Hip	17,6	9	22,6	12			
Both	29,4	15	22,6	12		0.795	0.672
Education							
Primary or lower secondary	54,0	27	50,0	25			
Upper secondary or further	46,0	23	50,0	25		0.160	0.689
Age							
Mean	75,63	6,68	73,47	6,01	-1,73		0.087
Median	74		73		-1.62		0.106

Figure 1 Flow chart

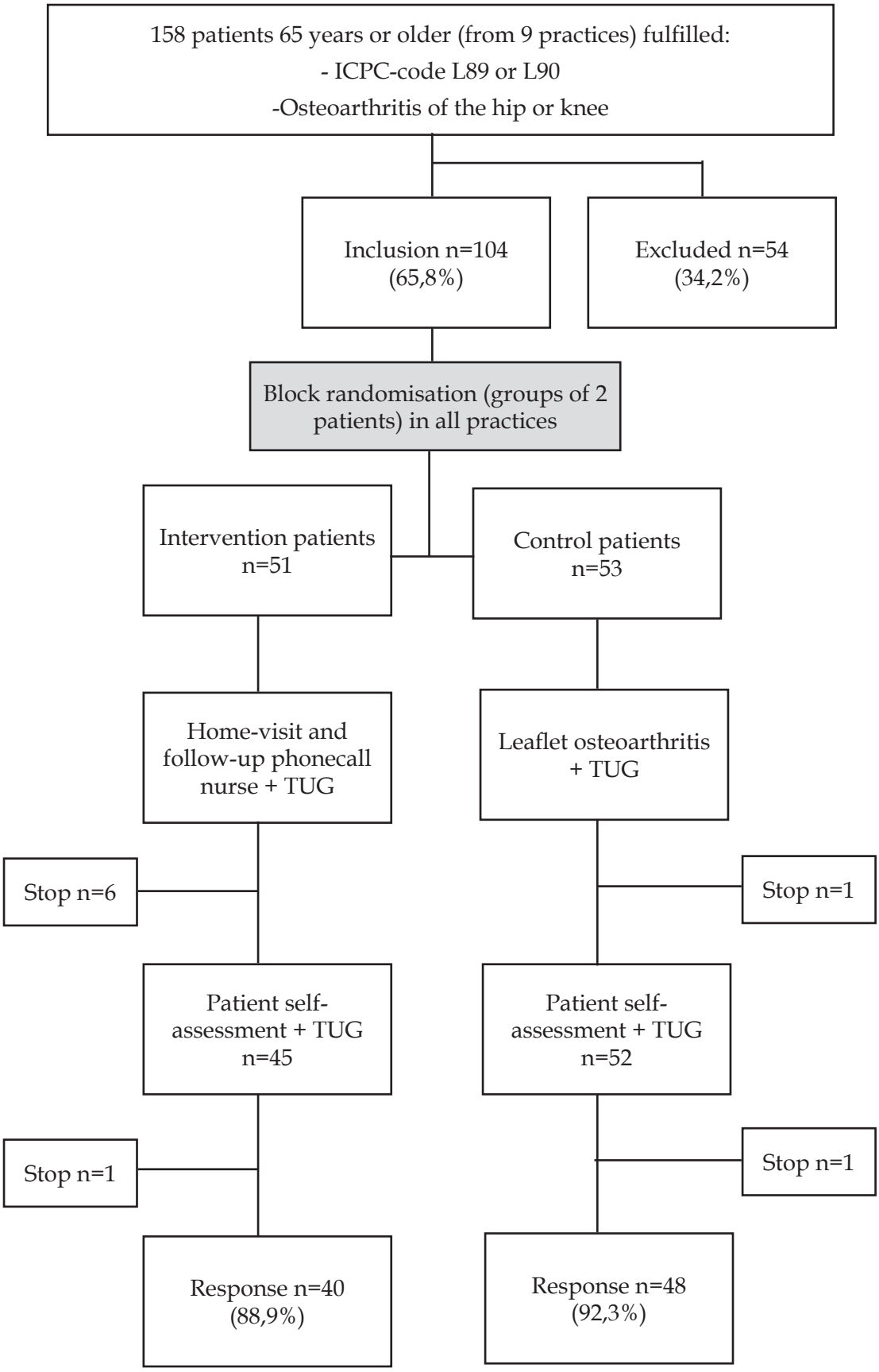

Table 2 Primary outcome measures

Outcome measure			Intervention				Control				Intervention to control comparison	
			Pre	N=51	Post	N=40	Pre	N=53	Post	N=48	t/Wald	p
		Range	Mean	SD	Mean	SD	Mean	SD	Mean	SD	t	
AIMS*#	Total	19-95	49,75	9,92	45,26	10,87	47,04	8,88	46,92	11,17	-2,12	0.04
	Physical	7-35	15,25	4,61	14,56	4,52	14,20	4,40	14,40	4,74	-1,97	0.36
	Symptoms	3-15	10,10	3,05	8,86	3,34	9,65	3,07	8,87	3,16	-0,05	0.96
	Social	4-20	11,94	2,70	11,40	2,91	11,43	2,42	11,88	2,76	-1,02	0.31
	Affect	5-25	12,27	3,35	11,19	3,95	11,23	3,05	11,48	3,64	-1,24	0.22
			≤12sec	>12sec	≤12sec	>12sec	≤12sec	>12sec	≤12sec	>12sec	Wald	p
Timed Up and Go#	Number per group		16	30	20	20	19	27	24	20		
	Valid % of group		34,8	65,2	50,0	50,0	41,3	58,7	54,5	45,5	0,36	0.55

*AIMS: The lower the scores, the better their functioning; #Adjusted for baseline scores

Secondary outcome measures

Intervention patients did not visit their GP or physiotherapist more often compared to the control group. In the intervention group 6/40 patients had 3 or more visits in the past half year to their GP, compared to 7/48 patients in the control group (p=0.81). 8/40 patients in the interventiongroup received physiotherapist treatment for their osteoarthritis complaints, compared to 6/48 patients in the control group (p=0.28). Medication use did not increase substantially in either of the groups, although there was a relatively larger increase in medication use in the intervention group. In the intervention group at baseline 22/51 patients used medication for osteoarthritis pain, whereas this was post-intervention 24/40 patients. In the control group the numbers were respectively, 29/53 and 23/48 (p=0.11).

Discussion

The hypothesis that our simple nurse-based intervention would improve an older OA patient's mobility and functional status was only partly confirmed in this study. A small significant difference on a self-reported osteoarthritis scale on functional status was found.

Both intervention and control patients' mobility showed a trend towards better mobility, as shown by TUG times. There was no significant difference between the two groups. There were no signs of negative side effects, such as more pain among intervention patients. This means that more physical exercise did not lead to exacerbations of pain, which is consistent with other studies[24]. Another negative aspect may be the medicalisation of OA because of these interventions, our study showed, however, no intervention induced visits to GP or physiotherapist.

So there may be a trend towards better functional status, but what is the clinical relevance of this outcome? It seems relevant as important aspects of patients' health status improved, such as social interaction, affect, pain and stiffness and physical functioning. Whether this effect continues to exist in the future remains to be seen. We think that this intervention may need longer follow-up, before patients are able to completely self-manage their symptoms. However, this assumption is not based on qualitative material or process evaluations of our intervention patients. Further exploration of the usefulness for patients of the intervention could help the implementation in daily practice.

Some limitations of this study could have interfered with the results. Although we tried to keep the questionnaire simple and short, there were a number

of missing values, as well as several missing TUG times, which was due to practical reasons. When considering this TUG, it was performed at home, on different chairs, and by different researchers. At baseline the assessors of TUG times were not blinded to the assignment of subjects to treatment group. There is some evidence that the type of chair does not matter[25], but these factors may have interfered in the validity of the values and may have introduced a bias. Furthermore in the interventiongroup there was a larger dropout compared to the control group, which may have caused some bias as well. Finally, the time period between the two measurements may have been too short to measure influences on health status and mobility.

In conclusion, the results from this study show that an intervention of minimal intensity may have positive effects on the health status of older OA patients. Before being able to conclude that this intervention is an easy to implement addition to usual primary care in the Netherlands for OA patients with mild OA symptoms, the study should ideally be repeated with larger numbers of patients from more practices and with a longer follow-up.

References

1 Woolf A, Pfleger B. Burden of major musculoskeltal conditions. Bull World Health Org 2005; 81:646-56.

2 Barlow JH, Turner AP, Wright CC. Long-term outcomes of an arthritis self-management programme. Br J Rheumatol 1998; 37:1315-9.

3 Hawley DJ. Psycho-educational interventions in the treatment of arthritis. Baillieres Clin Rheumatol 1995; 9:803-23.

4 Superio-Cabuslay E, Ward MM, Lorig KR. Patient education interventions in osteoarthritis and rheumatoid arthritis: A meta-analytic comparison with nonsteroidal antiinflammatory drug treatment. Arthr Care Res 1996; 9:292-301.

5 Mazzuca SA, Brandt KD, Katz BP, Chambers M, Byrd D, Hanna M. Effects of self-care education on the health status of inner-city patients with osteoarthritis of the knee. Arthritis Rheum 1997; 40:1466-74.

6 Felson DT, Chaisson CE. Understanding the relationship between body weight and osteoarthritis. Baillieres Clin Rheumatol 1997; 11:671-81.

7 Fransen M, McConnell S, Bell M. Exercise for osteoarthritis of the hip or knee. Cochrane Database Syst Rev 2003; CD004286.

8 van Baar ME, Dekker J, Oostendorp RA, Bijl D, Voorn TB, Lemmens JA et al. The effectiveness of exercise therapy in patients with osteoarthritis of the hip or knee: a randomized clinical trial. J Rheumatol 1998; 25:2432-9.

9 Minor MA, Hewett JE, Webel RR, Anderson SK, Kay DR. Efficacy of physical conditioning exercise in patients with rheumatoid arthritis and osteoarthritis. Arthritis Rheum 1989; 32:1396-405.

10 Penninx BW, Rejeski WJ, Pandya J, Miller ME, Di Bari M, Applegate WB, et al. Exercise and depressive symptoms: a comparison of aerobic and resistance exercise effects on emotional and physical function in older persons with high and low depressive symptomatology. J Gerontol B Psychol Sci Soc Sci 2002; 57: 124-32.

11 Mangione KK, McCully K, Gloviak A, Lefebvre I, Hofmann M, Craik R. The effects of high-intensity and low-intensity cycle ergometry in older adults with knee osteoarthritis. J Gerontol A Biol Sci Med Sci 1999; 54:M184-M190.

12 Solomon SD, McMurray JJV, Pfeffer MA, Wittes J, Fowler R, Finn P, et al. Cardiovascular Risk Associated with Celecoxib in a Clinical Trial for Colorectal Adenoma Prevention. N Engl J Med 2005; 352:1071-80.

13 Heuts PH, Bie R de, Drietelaar M, Aretz K, Hopman-Rock M, Bastiaenen CH, Metsemakers JW, van Weel C, van Schayk O. Self-management in osteoarthritis of hip or knee: a randomized clinical trial in a primary health care setting. J Rheumatol 2005; 32:543-9.

14 Wetzels R, Wensing M, van Weel C, Grol R. A consultation leaflet to improve an older patients' involvement in general practice care. Health Expectations, in press.

15 West RL, Thorn RM. Goal-setting, self-efficacy, and memory performance in older and younger adults. Exp Aging Res 2001; 27:41-65.

16 Nelson E, Wasson J, Kirk J, Keller A, Clark D, Dietrich A, et al. Assessment of function in routine clinical practice: description of the COOP Chart method and preliminary findings. J Chronic Dis 1987; 40:55S-69S.

17 Taal E, Rasker JJ, Riemsma RP. Psychometric properties of a Dutch short form of the Arthritis Impact Measurement Scales 2 (Dutch-AIMS2-SF). Rheumatology 2003; 42:427-34.
18 Podsiadlo D, Richardson S. The timed "Up & Go": a test of basic functional mobility for frail elderly persons. J Am Geriatr Soc 1991; 39:142-8.
19 Ren XS, Kazis L, Meenan RF. Short-form Arthritis Impact Measurement Scales 2: tests of reliability and validity among patients with osteoarthritis. Arthritis Care Res 1999; 12:163-71.
20 Lin MR, Hwang HF, Hu MH, Wu HD, Wang YW, Huang FC. Psychometric comparisons of the timed up and go, one-leg stand, functional reach, and Tinetti balance measures in community-dwelling older people. J Am Geriatr Soc 2004; 52:1343-8.
21 Power calculator. http://calculators.stat.ucla.edu/powercalc/. 2005.
22 Vickers AJ, Altman DG. Statistics Notes: Analysing controlled trials with baseline and follow up measurements. BMJ 2001; 323:1123-4.
23 Bischoff HA, Stahelin HB, Monsch AU, Iversen MD, Weyh A, von Dechend M, et al. Identifying a cut-off point for normal mobility: a comparison of the timed 'up and go' test in community-dwelling and institutionalised elderly women. Age Ageing 2003; 32:315-20.
24 Exercise Prescription for Older Adults With Osteoarthritis Pain: Consensus Practice Recommendations. J Am Geriatr Soc 2001; 49:808-23.
25 Eekhof JA, de Bock GH, Schaapveld K, Springer MP. Short report: functional mobility assessment at home. Timed up and go test using three different chairs. Can Fam Physician 2001; 47:1205-7.

Discussion

10

The key-questions addressed in this thesis were related to what older patients and GPs expect and prefer when it comes to involvement, and what suitable interventions are in this respect. The first question was answered by using a qualitative approach. Involvement of older patients in their general practice care is not something to be taken for granted, not something that is to be automatically expected by doctors or policy makers. The elderly and their GPs were not unwilling regarding involvement, but several factors interfere in this process. The second question was answered using a systematic literature review and several related intervention studies. This question cannot be answered convincingly in a straightforward way. There is little evidence of effective interventions and it may well be that only a cultural shift among the elderly towards involvement will lead to more involvement. It is questionable whether one should try to quicken this development, because many older patients will not be ready for this change.

Main conclusions of exploring different views on involvement

Older patients had an ambiguous attitude towards involvement, they had positive expectations, but also worries about increased responsibility. Some of the less obvious barriers for older patients to involvement were: the tension they felt in consultations; the fixed pattern of 'not becoming involved' in consultations; the feelings of doing a job which they felt not capable for. Older people considered some facilitators to involvement: taking a family member or friend to the consultation; preparing the consultation by writing down questions for the GP; and a personal GP with enough attention and a stimulating attitude.

GPs considered patient involvement as a process taking place during consultations and expected positive outcomes, however there was some fear of lengthening the consultations. GPs considered their lack of time as the main barrier to involvement. The barriers GPs perceived were also related to older patients, for example older patients' feelings of respect for doctors, their lack of experience in being involved and possible mental and physical impairments. Barriers to involvement were not influenced by the organisation of health care systems or cultural factors. The variation within countries in perceived barriers proved to be larger than the variation across countries.

Patients thought that using patient satisfaction questionnaires provided the GP with more information, functioned as a basis for change, increased patients' self-confidence and made them more conscious of what to expect. Barriers for their use were cognitive impairment among patients and the fear that other

patients would give social desirable answers.

Patient information leaflets supported patients' memories, educated patients and promoted their self-responsibility. The barriers were cognitive impairment among patients and the fear that the leaflets would give them false impressions of what to expect.

Data from a cohort-study showed that the most important determinants for older people to visit a GP were pain and the belief that others, particularly the physician, have much influence on the health status. Furthermore, our study suggested that a strong orientation on self-management does not necessarily lead to underreporting of health problems, on the other hand, a weak self-management orientation may imply that medical advice is sought for minor problems.

Discussion on exploring different views on involvement

Our study showed that GPs and patients regard patient involvement as a feature of the doctor-patient relationship. It is difficult for them to have a clear idea of how to achieve involvement. The main barrier related to the elderly is their relative passive and dependent attitude, which is based on several feelings and cognitions, as shown further on. This attitude of older patients in GP consultations has been reported before[1;2]. Elderly are reluctant in taking responsibility for medical decisions[3], their typical reason for declining participation was 'The layman is not qualified to make decisions'. Other qualitative additions to justify their preference for minimal information were: 'I'm not qualified'; 'I need as little to worry about as possible'; 'It's the doctor's job, he'll take care of the details.'[4]. And they find it difficult to adequately describe their symptoms[5]. A recent review shows that older patients have a preference for a more dominant (traditional) physician[6]. They also prefer, like all patients, continuity of care with the same physician for more serious problems[7]. Finally, it seems that amongst older patients the preference for information is larger than for becoming involved in medical decisions[8]. Besides this, our study showed that older people were also open-minded to improvement of their role in consultations, and they were willing and able to use some aids. Although they were open-minded to improvement, it is clear that this will not happen automatically. Since they are already quite satisfied with their care[9], it may need more energy to help them to modify their behaviour in consultations.

Older patients' reasons for their rather passive behaviour may be found in the historical time in which they grew up, in which it was common to be

less demanding and more acceptant of authorities. Besides this some older people view the process of aging as one that is inevitably linked with disease and therefore they may not contact the doctor with common symptoms that can be relieved[5]. Communication by some older patients is also made more difficult by age-related physiological changes as well as disruptions in the social and physical environment. Impaired hearing and vision can impede communication, while deficits in mobility can lead to doctor impatience with the length of interaction. Environmental changes include loss of spouse and friends, new living arrangements, and unfamiliar health care settings[11].

The GPs' main barrier was lack of time, this includes the fear of lengthening of consultations when patients take a more active role. It is questionable whether this logical feeling is completely appropriate. A recent randomised controlled trial showed that when GPs prompted patients to ask them about their concerns the consultation time increased with 10% (from 10 to 11 minutes)[12]. Those patients were more satisfied with the given professional care; this improved satisfaction is partly due to longer consultations, and partly due to asking about patients' concerns. Patients' desire for longer consultations may be mostly correlated with dissatisfaction with the emotional aspects of the consultation and subsequently a lower intention to comply with the recommendations[13]. Maybe the right way forward is to change the way time is spent in consultations. Better eliciting of concerns and preferences may lead to involved and satisfied patients, without spending more time.

With respect to patient satisfaction questionnaires and patient leaflets, it has been found before that this resource is under-utilised by doctors[14]. What are causes for this? It seems difficult for patients and doctors to oversee the large amount of leaflets. Not all leaflets are readable for everyone, an explorative study suggested that developing leaflets is influenced by various complex organisational processes and that developers face a need to cope with organisational politics, goal conflicts and various other pressures[15]. In the Netherlands the Dutch College of General Practitioners has a wide variety of leaflets and information letters based on the latest evidence, that overcomes the stated difficulty. Patient satisfaction questionnaires are even more not daily general practice. Finding out what customers think of your company is normal in the business world, however not yet in general practice. However, this may be normal in the near future for general practitioners as well, as they more and more are seen and see themselves as firms as well.

The cohort study showed that elderly were less inclined to seek advice for non-painful problems, such as hearing loss or vision problems, although effective treatment or rehabilitation may be available. A recent large survey showed that the strongest predictors for seeking help by elderly are self-reported

general health and the number of chronic diseases they have[16]. Other factors of importance were anxiety and frequent contacts with family and friends. In analogue to the latter, it may well be that the shared help seeking behaviour within younger families[17] is also applicable to older people and their children. Meaning that besides the previous mentioned predictors of consultation the family 'tradition' of when to consult is important as well.

It is a complex field of different influencing factors. In order to try to improve the involvement of older patients when desirable, GPs may support their older patients more, for example by asking them specific questions (about their experiences, needs and preferences), giving room to patients' question lists, by using family members in the consultation, and by providing education and counselling to support self-management in patients. It is questionable whether this will become daily practice, a start is that our study, confirmed by other studies, showed that GPs think that involvement of patients is important[18]. This feeling of importance may lead to creation of time in the future for support of the elderly. This opposes findings in another study, which showed that some doctors view older patients as less desirable patients, spend less time with them and respond less to their psychosocial concerns[19].

Limitations

The main limitation of the interview studies was related to the interpretation of the multi-lingual qualitative material. By using specific instructions, repeated checks of researchers in each country and a structured approach to analysis, we tried to reduce the influence of those problems as much as possible. Nevertheless, the international nature of this study precluded an in-depth analysis. On the other hand the comparable findings in the high number of interviews from eleven different countries may only strengthen the conclusions.

As the elderly are a heterogeneous population group, we stratified participants according to age group (<80 years old and ≥ 80 years old), gender, practice locality and health status. The social economic status is missing in this stratification, but we used practice locality as a global substitute for this. By using the stratification in selecting participants a broad range of ideas, preferences and expectations was generated. This was in accordance with our intention, as the involvement of older patients is a hardly explored area. The nature of a qualitative analysis, however, did not allow us to identify differences between the various groups.

It may be that the selection of patients through GPs biased our results, selected patients may have given a too rosy picture of reality. The international nature

of our study, in which selection procedures had to be more or less the same, precluded recruitment through, for example, the media. However, we think that the participants in their interviews also mentioned critical aspects of involvement and of their GP. Besides this, the interviewers did explicitly state that they had no connection with the participant's general practice and that the results were processed anonymously and would not reach their GP.

The cohort study relied on patient–reported measures and only had limited information on patient characteristics. It may be that this has interfered with the results, as patients tended to report less physician utilisation than recorded in computerised provider records[12].

Main conclusions of exploring methods for improving involvement

Our review showed that specific instruments to involve older people in their health care have hardly been tested in well designed studies. The results from reviews about other age groups[20;21] may be applied to the elderly as well, but this remains unclear. In our intervention studies it came up that patients were highly satisfied with their involvement and GP behaviour during consultations. Our consultation leaflet implementation did not improve the quality of consultations on the items measured, and its usefulness was not obvious for GPs and patients. Participants who used the leaflet were already accustomed to do so. The intervention programme therefore did not seem to facilitate involvement as we expected. It may be that older patients already perceive to be sufficiently involved, on the other hand the strategy may not be the right one. We conclude that unselected use of this intervention for all older should not be pursued.

The low-intensity self-management programme for patients with osteo-arthritis, educated by a nurse, had moderately positive effects on patients health status and may therefore be promising as an addition to usual care in the Netherlands. It did not have negative side-effects, for example, it did not lead to increased GP or physiotherapist visits.

Discussion on exploring methods for improving involvement

The low numbers of included studies in our systematic review was striking. What could be a reason for this lack of information on older peoples' involvement in their own care? There has been written a lot about involvement in relation to the population, but not in specific relation to the elderly. Are we sceptical towards the importance of an older patient's involvement? Or is that we think older patients should not be approached differently, and therefore the results of other studies may be applicable to older patients as well? The results of our review compared to two reviews[20;22] with younger people do not contradict. Maybe their conclusions are valid for the elderly as well, but we are not certain.

Our patient-directed implementation programme with a consultation leaflet was not successful in facilitating and increasing patient participation, this in contrary to interventions in a recent review[22]. A comment on this review is that it included all age groups. Another finding with respect to written materials is that a general leaflet that encouraged patients to raise concerns during their GP visit improved patients' satisfaction and perceived communication[23]. Another review of the literature led to a number of conclusions[24]: with respect to individuals who seek health care. It was concluded that instruments for needs assessment, such as scoring lists completed before a consultation, could be helpful; patient-held records are probably useful in specific subgroups of patients, such as patients with chronic illness. So, despite the fact that these findings created expectations with respect to the effectiveness of our intervention, the study that evaluated the consultation leaflet showed no effect.

What may be reasons for this? It may well be that an abstract non-disease specific intervention, i.c. a general leaflet about how to communicate and become involved, is not the most effective way forward. One needs specific skills to be able to evaluate your own consultations on a meta-level in order to improve these consultations. The education level of older patients is often lower, and cognitive skills deteriorate more often when you get older. Therefore it becomes more difficult to see what is good or less good in your interaction with the doctor. It is also the case that many older patients are used to solve problems themselves, or do not see specific symptoms as a problem. However when they are visiting a GP they more or less expect him/her to solve their problem. This is illustrated by a recent telephone survey, in which trust in medical profession was correlated with a passive role during consultations and which showed that although the majority of elderly would like to share control, a significantly higher proportion wants the physician to

have complete control compared to other age groups[25]. It may therefore be a disappointment when they need to change or solve something themselves. This disappointment should be adressed to make such abstract, non-disease specific interventions work. Patients need to see the profit they gain from becoming more involved, they should be educated on it. This last aspect seems to be a fundamental, cultural aspect; a fundamental change is required before such interventions aimed at involvement can become effective.

As mentioned earlier, we should be careful not to force older patients to become involved. The danger for medicalisation always exists on the background. One should therefore always leave the initiative of the different interventions to improve participation with the older patients, in order to respect their autonomy.

Since we were not effective in finding generic instruments to stimulate involvement, we created a disease-specific instrument with the same aim: improve involvement, but this time with self-management. The osteoarthritis (OA) patients seemed to profit from our intervention. But long-term effects are not (yet) known and should be followed. It is also interesting to know whether patients have improved self-management and whether this made their GP visits different for other complaints as well. We already knew that more intensive self-management programmes for OA were effective on mobility and health status. In our study we showed that a low-intensity self-management intervention was also effective. Because of its lower intensity it may be more feasible and more easy to implement in normal practice. Experiments with wider implementation of this intervention should be developed now.

Limitations

As our review was committed to strict inclusion criteria, one could argue that more studies could have been found when loosening these criteria in order to explore more interventions on facilitating involvement. However, as explained earlier it was not expected that more studies could be found when loosening the criteria.

The limitations of the consultation leaflet implementation programme were mainly in the outcome measurements, i.c. the questionnaires. They were too difficult for many older patients, which led to low response rates and several missing values. Another limitation may be the design of this study, ideally we should have chosen a design in which pre- and post-intervention patients were similar. However, this was not possible for practical reasons. To our opinion this design is acceptable, as it rules out the time effect and there were no major differences between the different groups, except for the overrepresentation of

male patients in the post-intervention control group. The limitation mentioned in section 1 applies also to chapters 7 and 8. The elderly are a heterogeneous population group, we tried to include a heterogeneous sample of older patients by selecting them from consecutive GP consultations. However, differences between the various groups were not identified using a subgroup analysis yet. This may be worthwhile in order to identify whether the heterogeneity has an influence on experiences, preferences and effectivity of involvement.

With respect to the osteoarthritis study we managed to develop a good randomised controlled trial with low patient dropout. A limitation may be that we do not have a clear sight on which goals different patients had set to improve their symptoms. This gave us less insight in the process of change in health status and mobility. Furthermore, the study time may be too short to measure changes in health status and mobility.

Recommendations

This thesis showed that improving older patients' involvement in their own health is an important but complex process. It is a very relevant part of patient-centred care and one of the cornerstones of general practice. We therefore should continue to focus on better involving of older patients in health care. Although we did not find a straightforward way towards involvement, older patients and GPs felt that it matters.

The findings of this thesis may have some consequences for the way older patients are able to survive in the new health insurance system in the Netherlands in which patients more and more become responsible for their own care[26]. People are increasingly forced to use health care in an appropriate way, and financial incentives are given to promote this. It remains questionable whether the elderly are prepared for this. It requires an active role of patients and adequate self-management skills in order to use health care in a most adequate way. This thesis shows that this will not happen automatically. One recommendation is that older patients should be supported more in their use of health care. Education and support should be tailored to individual patients. On a consultation level one may think of for example (pre-consultation) face-to-face sessions with practice assistants in addition to written supportive materials. As an alternative, doctors could pay more attention to the fact that older patients are not used to be(come)ing involved, and may try to stimulate this in different consultations over time.

With respect to the osteoarthritis study the intervention seemed promising as an addition to current general practice. It is particularly applicable for people

with mild symptoms. Further research should focus on wider implementation of this intervention and on the effects over a longer period. Also patients' self-management skills should probably be maintained over time, by for example repeatedly contacts with a practice assistant or nurse.

Further research

Future research should focus on more structural interventions for supporting older patients in their use of general practice care. The interventions should include more than written materials and GP instructions. We think that older patients need more face-to-face contacts with for example a practice assistant or a nurse in addition to written materials. We think that there should be a balance in respecting patients' autonomy and stimulating their active participating in their own care. The studies should be randomised trials with a complete design, appropriate number of older patients and should preferably include objective health outcomes besides a measure for involvement. This measure for involvement may be a combination of patients' self-reported behaviour and patients' self-reported evaluation, but should maybe also include an objective observation of patients' involvement.

Future research elaborating on the osteoarthritis study should include a longer follow-up and should be implemented for example in a large region, in order to come to the conclusion that it is an asset to daily general practice.

References

1 Smith RA, Woodward N, Wallston B, Wallston K, Rye P, Zylstra M. Health care implications of desire and expectancy for control in elderly adults. J Gerontol 1988; 43:1-7.

2 Woodward N, Wallston B. Age and health care beliefs: self-efficacy as a mediator of low desire for control. Psychol Aging 1987; 2:3-8.

3 Frosch D, Kaplan R. Shared decision making in clinical medicine: past research and future directions. Am J Prev Med 1999; 17:285-94.

4 Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. Ann Intern Med 1980; 92:832-6.

5 Morgan R, Pendleton N, Clague JE, Horan MA. Older people's perceptions about symptoms. Br J Gen Pract 1997; 47:427-30.

6 Jung HP, Baerveldt C, Olesen F, Grol R, Wensing M. Patient characteristics as predictors of primary health care preferences: A systematic literature analysis. Health Expect 2003; 6:160-81.

7 Schers H, Webster S, van den Hoogen H, Avery A, Grol R, van den Bosch W. Continuity of care in general practice: a survey of patients' views. Br J Gen Pract 2002; 52:459-62.

8 Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. Br J Gen Pract 1999; 49:477-82.

9 McCann S, Weinman J. Empowering the patient in the consultation: a pilot study. Patient Educ Couns 1996; 27:227-34.

11 Haug M, Ory M. Issues in elderly patient-provider interactions. Res Aging 1987; 9:3-44.

12 McLean M, Armstrong D. Eliciting patients' concerns: a randomised controlled trial of different approaches by the doctor. Br J Gen Pract 2004; 54:663-6.

13 Ogden J, Bavalia K, Bull M, Frankum S, Goldie C, Gosslau M, et al. "I want more time with my doctor": a quantitative study of time and the consultation. Fam Pract 2004; 21:479-83.

14 Kenny T, Wilson RG, Purves IN, Clark J, Newton LD, Newton DP, et al. A PIL for every ill? Patient information leaflets (PILs): a review of past, present and future use. Fam Pract 1998; 15:471-9.

15 Gal I, Prigat A. Why organizations continue to create patient information leaflets with readability and usability problems: an exploratory study. Health Educ Res 2004; doi:10.1093/her/cyh009 .

16 Harris T, Cook DG, Victor CR, Beighton C, DeWilde S, Carey IM. Linking survey data with computerised records to predict consulting by older people. Br J Gen Pract 2004; 54:928-31.

17 Cardol M, Groenewegen PP, de Bakker DH, Spreeuwenberg P, van Dijk L, van den Bosch W. Shared help seeking behaviour within families: a retrospective cohort study. BMJ 2005; 330:882.

18 Ogden J, Ambrose L, Khadra A, Manthri S, Symons L, Vass A, et al. A questionnaire study of GPs' and patients' beliefs about the different components of patient centredness. Patient Educ Couns 2002; 47:223-7.

19 Giles H, Coupland N, and Wiemann JM. Communication, health and the elderly. 1990. Manchester University Press in association with the Fulbright Commission.
20 Griffin SJ, Kinmonth AL, Veltman MW, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. Ann Fam Med 2004; 2: 595-608
22 Harrington J, Noble LM, Newman SP. Improving patients' communication with doctors: a systematic review of intervention studies. Patient Educ Couns 2004; 52:7-16.
23 Little P, Dorward M, Warner G, Moore M, Stephens K, Senior J et al. Randomised controlled trial of effect of leaflets to empower patients in consultations in primary care. BMJ 2004; 328:441.
24 Wensing M, Elwyn G. Improving the quality of health care: Methods for incorporating patients' views in health care. BMJ 2003; 326:877-9.
25 Trachtenberg F, Dugan E, Hall MA. How patients' trust relates to their involvement in medical care. J Fam Pract 2005; 54:344-52.
26 Hoogervorst H. Toespraak van de minister van volksgezondheid, welzijn en sport. 26-1-2005. New Year reception NVZ.

Summary

Chapter 1

In this chapter the rationale for this thesis is explained. Consultations are one of the cornerstones of general practice. The chapter starts with a historical perspective of ideas and concepts of consultations, and more specifically it shows some models of communication between doctors and patients over time. It made clear that in the history of general practice, over the years patients' ideas, concerns and expectations have always been important and became even more important, as well as patients' active role in the decision phase of the consultations. It is important to stress that GPs clinical competence in combination with his empathy are crucial for patient-centred care. It is made clear that involvement in care is relevant and important, but it is not clear whether this is as obvious for the elderly as for other patient groups. The key-questions for this thesis were what older patients and GPs expect and prefer when it comes to involvement, and what suitable interventions are to improve involvement. Furthermore the ageing population and their (co)morbidity patterns are described. A short explanation of the disease-specific example (osteoarthritis patients) of how to involve patients is given. Next, the concept of involvement and the related concept of self-management are described. To overcome theoretical limitations of different forms of patient involvement, we used in this thesis the global term 'patient involvement', it is used to refer to concepts of 'enabling patients to take an active role in deciding about and planning their health care'. We focused on the involvement of patients in their own medical care. With 'self-management' we referred to patient behaviour, which keeps illness under control and minimises its impact on health and quality of life. It included for example also the decision to seek care. Different possible interventions to improve one's involvement in care were described, as well as current knowledge in effectiveness and possibilities in implementation. Not a lot is known about involvement of elderly. We therefore decided to explore this area by using a qualitative approach. In the second phase of the research project we used a more quantitative approach to evaluate different methods for improving an older patients' involvement. We hypothesised that cultural influences were important in the involvement of people in their care, we therefore evaluated our research questions partly in an international study, called IMPROVE. The chapter ends with an overview of our research questions.

Chapter 2

In this chapter the views and expectations of older patients were analysed. Positive and negative expectations, and factors that facilitated or impeded the involvement of older patients in their general practice care, are described. For this purpose we used semi-structured interviews with 28 older patients (70 years and older) in the region of Nijmegen. To ensure that as many different opinions could be enclosed, we included patients from different subgroups (for example patients who had a disease for a short episode, patients with a chronic illness, patients who recently heard that they have a lifethreatening disease, and non-attenders). The interviewed older patients had positive expectations of becoming involved. However, they also identified barriers to involvement such as not being used to become involved; feeling themselves lay persons in consultations; being nervous during consultations; and having cognitive (for example forgetfulness) and physical (for example slowness in undressing for physical examination, visual) impairments. Also the GP who has a lack of time and sometimes a lack of attention was mentioned as a barrier. Besides this, anxiousness of taking the wrong decisions or suddenly becoming more responsible for decisions was what older patients kept away from becoming more involved. A number of facilitating factors to involvement were mentioned by the older patients: taking a family member or friend to the consultation; preparing the consultation by writing down questions for the GP; and a personal GP with enough attention and a stimulating attitude. In conclusion, older patients had worries about increased involvement in their own general practice care, but they were open-minded to improve their involvement as they had positive expectations. Enhancing their involvement will need a gradual stimulation. GPs may have a role in this, by taking some of older patients' worries away.

Chapter 3

Now knowing older patients' views, in this chapter we determined GPs' barriers to the involvement of older patients in general practice care and identified variations between countries. We performed an international comparative study based on qualitative interviews with 233 general practitioners (GPs) in 11 countries. GPs thought of patient involvement as a process taking place solely during consultations. They thought that involving older patients had positive outcomes, but their main barrier was their lack of time. They mentioned barriers related to older patients, for example older patients' feelings of respect for doctors, their lack of experience in being involved and possible mental and physical impairments. We concluded that

increasing involvement of older patients is not easy and will only be effective when GPs have adopted a more developed concept of patient involvement and are supported with the different methods for achieving this. The range of appropriate interventions may be similar in all countries, as there were no signs of main differences between countries.

Chapter 4

On the basis of our findings in the two previous chapters, we evaluated two methods to facilitate older patients' involvement: namely patient information leaflets and patient satisfaction questionnaires. We compared older patients' views with the GPs' views on these two types of methods. In seven countries (Austria, Denmark, Germany, The Netherlands, Portugal, Slovenia and Switzerland) 146 GPs and 284 patients aged 70 and over were interviewed about the use and the acceptability of these two methods. The arguments for using patient satisfaction questionnaires were that they would provide the GP with more information, they may function as a basis for change, increase patients' self-confidence and make them more conscious of what to expect. Barriers for their use were cognitive impairment among patients, the fear that they would not answer honestly and the opposition some people may have to written material. The arguments for patient information leaflets were that they could support patients' memories, educate patients and promote their self-responsibility. The barriers were cognitive impairment among patients and fear that they would give them false impressions of what to expect. Both instruments were generally well accepted by both GPs and patients. Their use seemed to be dependent upon the individual GP's attitude and the patients' cognitive capacities.

Chapter 5

In this chapter we determined what effect self-management orientations and perceptions of health problems had on older adults' frequency to seek medical advice. This in order to know whether strong self-management (as a part of strong involvement) has an influence on help-seeking behaviour. We used a population based prospective cohort study in thirty-four family practices in the Netherlands. All patients from the practices' population aged between 70 and 80 years, living independently in the community were included. We used three surveys, containing questionnaires that included age, gender, education level, composition of household, general state of health and health locus of control. The most important determining factors for older people to visit their GP were pain and the belief that others, particularly the GP, have

much influence on their health status. Patients with a strong self-management orientation visited their GP as often as others.

We concluded that GPs should be aware of unreported non-painful health problems in older adults, and when possible, anticipate on their existence. Strong self-management in older patients does not necessarily lead to fewer contacts in primary care.

Chapter 6

In order to come to effective interventions we first give in this chapter a review of the literature, to identify current interventions in primary care that improve older patients' involvement in their health care. The outcome measures used to assess these interventions were described and a summary is given of their effects. We searched broadly in several databases. We included Randomised Controlled Trials (RCTs) or Controlled Clinical Trials (CCTs) of interventions to improve involvement in a single consultation or an episode of primary medical care of older patients (≥ 65 years). We found four studies, in which three different interventions were examined: 1. Visit preparation booklet; 2. Pre-visit session; 3. Group programme. Interventions and outcome measures were heterogeneous. Primary outcome measures were questioning behaviour, self-reported active behaviour and visit evaluation. Three studies were randomised trials (with a post-test assessment only), one study had a quasi-random design. Two studies found a positive effect on question asking because of a pre-visit session; no other obvious results were found. Overall this review gives too limited evidence to draw firm conclusions on effectiveness of specific instruments to improve involvement of older people. We conclude that there is little evidence of the effectiveness of interventions in the elderly. The available data were in line with experiences in younger patients.

Chapter 7

In this chapter we analysed the implementation of a programme for involvement of older patients aged 70+ in general practice and to detect quality changes after its implementation. The study was performed in 11 European countries as an uncontrolled study in which GPs and patients answered a questionnaire before receiving and after having received an intervention. The intervention aimed at motivating, instructing and facilitating GPs and older patients to increase patient involvement during the consultation by use of a specially designed Consultation Leaflet. Valid data from seven countries were available. Questionnaires were answered and returned by 900 patients and 79 GPs in the pre-intervention phase and 575 patients and 58 GPs after

the intervention. In the intervention group 43% of the patients thought that the Consultation Leaflet had improved the consultation and 62% of the GPs found it to be useful. There were no significant differences between the pre- and the post-intervention patient perceptions of the level of involvement, evaluations of consultations and perceptions of feeling enabled to deal with their health situation. In conclusion, the quality of consultations as measured by patient satisfaction and patient enablement did not improve as a result of the intervention, but nearly half of the patients and two thirds of the GPs found the intervention to be useful. Unselected use of this intervention on all patients cannot be advised. Future studies should focus on the applicability and benefits of the methods for special patient groups.

Chapter 8

In the Netherlands the study described in chapter 7 was performed using a control group as well. In this chapter the evaluation of the effects of a programme to enhance the involvement of older patients in their consultations in general practice are described using a cluster-randomised trial. Patients aged 70 years and over from 25 general practices in the Southeast part of the Netherlands were approached. Patients in the intervention group received a leaflet aimed at preparing the consultation and GPs received an outreach visit to optimise older patients' involvement when visiting their GP. Patients in the control group received usual care. Pre- and post-intervention questionnaires were used measuring involvement (COMRADE), enablement (Patient Enablement Index) and satisfaction with their care (EUROPEP). Pre-intervention 315 patients and post-intervention 263 patients were included. Subjects were satisfied with their involvement and GP behavioural during consultation. They felt the same or better enabled after the consultation. No differences in effect on involvement, enablement or satisfaction were found between intervention and control group. Of 318 patients who were sent the leaflet and visited their GP, 47 used the leaflet. Users were more accustomed to prepare themselves for consultations. Users reported more other mental problems compared to non-users. In conclusion, no relevant effects of the implementation programme on involvement, enablement or satisfaction were found. Other strategies are needed to enhance involvement of older patients in their care. Alternatively, older patients may perceive to be sufficiently involved.

Chapter 9

In this chapter the evaluation of a minimal intensity intervention to improve older osteoarthritis patients' selfmanagement is described. Patients with hip

or knee osteoarthritis participated in a randomised controlled trial in nine general practices in the Netherlands. Fifty-one patients were randomised to the intervention and 53 to control group. Our outcome measures were mobility and health status. To measure mobility we used the Timed Up and Go test (TUG), an easy objective mobility test performed at home. Health status was measured using a arthritis specific self-assessment list (Dutch AIMS SF); it includes pain, stiffness; physical functioning, social status and mood symptoms. Patients in interventiongroup improved significantly on sumscore of Dutch AIMS SF. There was no difference in shift towards normal TUG times between the intervention group and the control group. GPs or physiotherapists were not visited more often by patients in the intervention group. There seemed to be a trend towards more medication use in the intervention group, but this was not significant.

This study showed that with a minimal intensity intervention a trend towards better functional status may be reached. It could therefore be something which may be a good addition to current OA care in Dutch general practices.

Chapter 10

In this chapter the results of the different studies are discussed using current literature. Its implications are discussed, as well as some recommendations are given. The findings suggest that one may not take older patients' involvement in their general practice care for granted. This thesis showed that older patients' involvement is an important but complex process. It is as a part of patient-centred care and one of the cornerstones of general practice. We therefore should continue to focus on involvement of older patients. Although we did not find a straightforward way towards involvement, older patients and GPs felt that it matters.

Samenvatting

Hoofdstuk 1

In dit hoofdstuk wordt de rationale van dit proefschrift uitgelegd. Omdat een spreekuurbezoek een van de hoekstenen van de huisartsgeneeskunde is, start het hoofdstuk met een historisch perspectief van ideeën en concepten met betrekking tot spreekuurbezoeken. Er worden verschillende modellen van communicatie tussen dokters en patiënten beschreven. Het wordt duidelijk dat in de geschiedenis van de huisartsgeneeskunde de ideeën, gedachten en verwachtingen van patiënten altijd al belangrijk zijn geweest en steeds belangrijker zijn geworden. Dit geldt ook voor de actieve rol die patiënten hebben in de beslissingsfase van het consult. Het is belangrijk te benadrukken dat de klinische competentie van huisartsen in combinatie met empathie cruciaal zijn voor patiëntgerichte zorg (patient-centred care).

Het wordt duidelijk dat inbreng en betrokkenheid (involvement) van mensen in hun zorg relevant en belangrijk zijn, maar het is niet duidelijk of dit net zo vanzelfsprekend is voor ouderen als voor andere patiëntengroepen. De kernonderzoeksvragen voor dit proefschrift zijn: wat zijn verwachtingen en voorkeuren van ouderen en huisartsen met betrekking tot inbreng en betrokkenheid in hun huisartsenzorg? En vervolgens, wat zijn mogelijke interventies om de gewenste inbreng en betrokkenheid te vergroten?

De vergrijzende populatie en bijbehorende (co)morbiditeit wordt beschreven. Evenals een korte uitleg van hoe bij het ziekte-specifieke voorbeeld (artrose patiënten) de gewenste inbreng en betrokkenheid van patiënten vergroot kan worden.

Vervolgens wordt het concept van inbreng en betrokkenheid, alsmede het hieraan gerelateerde zelfmanagement beschreven. Om theoretische beperkingen van verschillende vormen van patiënteninbreng en betrokkenheid te vermijden, wordt in dit proefschrift de volgende definitie gehanteerd: 'Het mogelijk maken voor patiënten om een actieve rol te nemen bij beslissingen over en plannen van hun gezondheidszorg'. In het proefschrift ligt de focus op inbreng en betrokkenheid van patiënten bij hun eigen medische gezondheidszorg. Zelfmanagement wordt beschouwd als een onderdeel van deze inbreng en betrokkenheid; zelfmanagement is gedrag van patiënten, dat ziekten onder controle houdt en dat de impact op gezondheid en levenskwaliteit minimaal houdt. Het houdt dus bijvoorbeeld ook in de beslissing om zorg te zoeken. Verschillende interventies om de inbreng en betrokkenheid van patiënten te vergroten worden beschreven, alsmede de huidige kennis van effectiviteit hiervan en de mogelijkheden voor implementatie. Er is niet veel bekend

over de inbreng en betrokkenheid van ouderen. Daarom is gekozen voor een kwalitatief onderzoek om dit gebied te exploreren. In de tweede fase van het onderzoek is een kwantitatieve aanpak gebruikt om verschillende methoden ter bevordering van inbreng te verbeteren te evalueren. Een hypothese was dat culturele invloeden van belang zijn bij inbreng van mensen in hun zorg; daarom zijn de onderzoeksvragen gedeeltelijk in een internationale studie getoetst. De studiegroep heette IMPROVE. Het hoofdstuk eindigt met een overzicht van de onderzoeksvragen.

Hoofdstuk 2

In dit hoofdstuk is de analyse beschreven van de gedachten en verwachtingen van ouderen omtrent hun inbreng in en betrokkenheid bij hun huisartsenzorg weergeeft. De analyse is gebaseerd op semi-gestructureerde interviews met 28 ouderen (70 jaar of ouder) uit de regio Nijmegen. Om ervoor te zorgen dat zoveel mogelijk verschillende gedachten, verwachtingen en meningen werden gevonden, sloten we patiënten in uit verschillende subgroepen. Bijvoorbeeld patiënten met een kortdurende ziekte, patiënten met een chronische ziekte, patiënten met een levensbedreigende ziekte en mensen die nooit het spreekuur bezoeken. De geïnterviewde ouderen hadden positieve verwachtingen van inbreng en betrokkenheid bij hun huisartsenzorg. Maar ze noemden ook een aantal belemmeringen: bijvoorbeeld ze zijn niet gewend om inbreng te hebben, ze voelden zichzelf leken in de spreekuurbezoeken, soms zijn ze gespannen als ze naar de dokter gaan. En er zijn soms cognitieve of fysieke problemen waardoor hun inbreng en betrokkenheid beperkt blijft. Ook een huisarts die maar beperkt de tijd heeft of een tekort aan aandacht laat zien kan belemmerend werken voor ouderen. Een toename van inbreng en betrokkenheid werd deels met angst tegemoet gezien, omdat men angstig was om verkeerde beslissingen te nemen en/of omdat men meer verantwoordelijkheid kreeg in beslissingen. Bevorderend op inbreng werkt het meenemen van een familielid of bekende naar het spreekuur, evenals het voorbereiden van het spreekuurbezoek door bijvoorbeeld vragen aan de huisarts op te schrijven. En verder een huisarts met een persoonlijke benadering en die aandacht en tijd heeft. Concluderend hebben ouderen zorgen over toename van hun inbreng en betrokkenheid in hun eigen huisartsgeneeskundige zorg, maar staan ze er wel voor open en hebben ze ook wel positieve verwachtingen. Het stimuleren van hun inbreng zal geleidelijk aan moeten gebeuren. Huisartsen kunnen hierin een rol vervullen door een deel van de zorgen weg te nemen.

Hoofdstuk 3

Nadat we ideeën en verwachtingen van ouderen geïnventariseerd hadden, onderzochten we in dit hoofdstuk de factoren die voor huisartsen een rol speelden bij inbreng en betrokkenheid van ouderen in hun huisartsenzorg. Daarnaast hebben we gekeken naar internationale variatie hierin. We hebben hiertoe een internationale vergelijkende studie uitgevoerd, waarbij we 233 huisartsen uit 11 landen hebben geïnterviewd. Huisartsen zagen de inbreng en betrokkenheid van hun patiënten als iets wat plaatsvond tijdens spreekuurbezoeken. Ze hebben het gevoel dat patiënteninbreng positieve uitkomsten heeft, maar hun voornaamste belemmering hiertoe was de beperkte tijd. Er werden een aantal belemmerende factoren bij oudere patiënten genoemd, zoals hun respect voor doktoren, hun beperkte ervaring in het hebben van inbreng en mogelijke cognitieve en/of fysieke beperkingen. We concludeerden dat het vergroten van inbreng en betrokkenheid van oudere patiënten niet gemakkelijk is, en alleen effectief zal zijn als huisartsen een uitgebreider idee van inbreng en betrokkenheid aanhouden en als ze gesteund worden middels verschillende methoden/instrumenten. Deze instrumenten kunnen gelijk zijn voor alle landen, daar er geen tekenen van grote verschillen waren tussen de verschillende landen.

Hoofdstuk 4

Op basis van de bevindingen in de vorige twee hoofdstukken evalueerden we twee methoden om de inbreng en betrokkenheid van oudere patiënten te faciliteren: patiënteninformatiefolders en patiëntensatisfactievragenlijsten. We vergeleken de meningen van oudere patiënten met die van huisartsen over deze twee methoden. In zeven landen (Oostenrijk, Denemarken, Duitsland, Nederland, Portugal, Slovenië en Zwitserland) werden 146 huisartsen en 284 patiënten geïnterviewd over de voors en tegens van het gebruik(sgemak) van deze twee methoden. Argumenten voor het gebruik van patientensatisfactie vragenlijsten zijn dat ze de huisarts voorzien van feedback, dat ze kunnen fungeren als basis voor veranderingen, dat ze het zelfvertrouwen van patiënten vergroten en deze zich meer bewust maken van wat ze kunnen verwachten. Belemmeringen in het gebruik waren de cognitieve beperkingen onder oudere patiënten, de zorg dat de vragen te rooskleurig worden ingevuld en de afkeer die sommige patiënten hebben van schriftelijk materiaal. Argumenten voor het gebruik van patiëntenfolders waren de steunfunctie van een folder om dingen te kunnen onthouden, ter educatie van patiënten en het bevorderen van hun zelfverantwoordelijkheid. Belemmeringen waren de cognitieve beperkingen onder patiënten en de angst dat er valse indrukken kunnen ontstaan van wat

ze kunnen verwachten. Beide instrumenten werden in het algemeen goed ontvangen door patiënten en huisartsen. Het gebruik ervan hangt af van de houding van de individuele huisarts en de cognitieve mogelijkheden van de oudere patiënt.

Hoofdstuk 5

In dit hoofdstuk bepaalden we wat de effecten van zelfmanagement en de verschillende percepties van gezondheidsproblemen waren op de frequentie van spreekuurbezoek van oudere patiënten. Dit is zinvol om te weten, daar een krachtig zelfmanagement (als onderdeel van een sterke betrokkenheid) mogelijk een invloed heeft op hulpzoekgedrag. We gebruikten de data van een prospectieve cohortstudie van ouderen uit 34 huisartspraktijken in Nederland. Alle patiënten tussen de 70 en 80 jaar uit deze praktijken werden geincludeerd wanneer ze zelfstandig in de gemeenschap woonden. We gebruikten drie vragenlijsten, waarin demografische kenmerken werden gevraagd, alsmede gezondheidsstatus en gezondheidsoriëntatie (health locus of control). De meest bepalende factoren voor ouderen om hun huisarts te bezoeken waren pijn en de overtuiging dat anderen, en met name de huisarts, veel invloed hebben op hun gezondheidsstatus. Patiënten met een sterke zelfmanagement oriëntatie bezochten hun huisarts net zo vaak als anderen.

Concluderend stelden we dat huisartsen alert moeten zijn op niet-gerapporteerde niet-pijnlijke gezondheidsproblemen bij ouderen en, indien mogelijk, dat ze anticiperen op het bestaan ervan. Krachtig zelfmanagement leidt niet per definitie tot minder contacten in de huisartsgeneeskunde.

Hoofdstuk 6

In dit hoofdstuk wordt de huidige stand van zaken op het gebied van inbreng en betrokkenheid van ouderen gegeven middels een overzicht van de literatuur. De interventies die geëvalueerd zijn in die studies werden beschreven, alsmede de gebruikte uitkomstmaten en een samenvatting van hun effecten. Er is breed gezocht in diverse zoeksystemen. RCTs en CCTs van interventies die gericht waren op de inbreng en betrokkenheid van ouderen (≥ 65 jaar) in een enkel spreekuurbezoek of een ziekte-episode in eerstelijnszorg werden ingesloten. We vonden 4 studies, waarin 3 verschillende interventies getest werden: 1. een spreekuurbezoek voorbereidingsboekje; 2. een voorbespreking van het spreekuurbezoek; 3. een groepsprogramma. De gevonden interventies en uitkomstmaten waren heterogeen. De primaire uitkomstmaten waren: vraaggedrag; zelfgerapporteerd actief gedrag en spreekuurbezoek evaluatie. Drie studies waren randomised trials (met een post-test design), één studie had

een quasi-random design. Twee studies lieten een positief effect op vraaggedrag zien, dit als gevolg van een voorbespreking van het spreekuurbezoek; verder waren er geen duidelijke resultaten. Dit review geeft te weinig bewijs om harde conclusies te trekken over de effectiviteit van specifieke instrumenten ter verbetering van inbreng en betrokkenheid van ouderen. Concluderend: er is te weinig bewijs betreffende de effectiviteit van interventies bij ouderen. Het beschikbare materiaal was in overeenstemming met de lijn van resultaten bij jongeren.

Hoofdstuk 7

In dit hoofdstuk analyseerden we de implementatie van een programma ter bevordering van inbreng en betrokkenheid van ouderen in de huisartsenzorg. We legden kwaliteitsveranderingen vast na de implementatie. De studie werd uitgevoerd in 11 Europese landen als een ongecontroleerde studie waar huisartsen en patiënten vragenlijsten beantwoordden voor en na ontvangst van de interventie. De interventie was gericht op motivering, facilitering en informering van huisartsen en ouderen om de inbreng van ouderen tijdens het consult te bevorderen. Er werd gebruik gemaakt van een folder huisartsbezoek, en de huisartsen werden door een onderzoeksmedewerker op de praktijk bezocht. Valide data waren beschikbaar van zeven landen. De vragenlijsten werden beantwoord en teruggestuurd door 900 patiënten en 79 huisartsen voor de interventie en door 575 patiënten en 58 huisartsen na de interventie. In de interventie groep had 43% van de patiënten het idee dat de folder het spreekuurbezoek had verbeterd en 62% van de huisartsen vond het zinvol. Er waren bij de patiënten geen significante verschillen voor en na de interventie in de perceptie van het niveau van inbreng, evaluaties van spreekuurbezoek en gevoel om te kunnen gaan met hun gezondheidssituatie. Concluderend: de kwaliteit van de spreekuurbezoeken gemeten middels patiënttevredenheid en mogelijkheden van patiënten om te gaan met hun probleem (enablement) verbeterde niet door de interventie. Bijna de helft van de patiënten en tweederde van het aantal huisartsen vond de interventie zinvol. Algemeen gebruik van de interventie kan niet worden geadviseerd. Toekomstige studies zouden zich toe moeten leggen op de toepassing en voordelen van de methode voor specifieke patiëntengroepen.

Hoofdstuk 8

In Nederland voerden we de studie uit hoofdstuk 7 uit met een controle groep. We beschrijven in dit hoofdstuk de resultaten van deze cluster-gerandomiseerde studie ter evaluatie van het programma om inbreng en betrokkenheid van

ouderen in hun huisartsbezoeken te vergroten. Patiënten van 70 jaar en ouder uit 25 huisartspraktijken in het Zuidoostelijk deel van Nederland werden benaderd. Patiënten uit de interventiegroep ontvingen een folder die ten doel had het voorbereiden van het huisartsbezoek en de huisartsen werden bezocht ter informering, motivering en facilitering van de inbreng en betrokkenheid van ouderen. Patiënten in de controlegroep ontvingen hun gebruikelijke zorg. Voor en na de interventie werden vragenlijsten gestuurd waarin inbreng en betrokkenheid (COMRADE), patiënten-mogelijkheden om te gaan met hun probleem (enablement; Patient Enablement Index), en tevredenheid met geleverde zorg (EUROPEP) werden gemeten. Voor de interventie werden 315 patiënten en na de interventie 263 geïncludeerd. Deelnemers waren tevreden met hun inbreng en huisartsgedrag tijdens het spreekuurbezoek. Hun mogelijkheden om te gaan met hun probleem bleven hetzelfde of verbeterden. Er werden verder geen verschillen gevonden. Van de 318 patiënten die de folder toegestuurd kregen gebruikten 47 de folder. De gebruikers waren meer gewend zich voor te bereiden op spreekuurbezoeken. Gebruikers rapporteerden meer geestelijke problemen vergeleken met niet-gebruikers. Concluderend waren er geen relevante effecten van het implementatie programma op inbreng, enablement of satisfactie. Er zijn andere strategieën nodig om de inbreng van ouderen in hun zorg te vergroten. Een alternatieve conclusie is dat ouderen vinden voldoende inbreng te hebben.

Hoofdstuk 9

In dit hoofdstuk evalueerden we een interventie die gericht is op de zelfmanagement vaardigheden van een oudere artrosepatiënt. De interventie was praktijkgericht en van minimale intensiteit om eventuele implementatie te vergemakkelijken. Patiënten met knie- en/of heupartrose namen deel in een patiënt gerandomiseerde studie, ze kwamen uit negen huisartspraktijken uit Elst en Arnhem. 51 patiënten werden gerandomiseerd naar de interventie- en 53 naar de controlegroep. Onze uitkomstmaten waren mobiliteit en gezondheidstatus. Om mobiliteit te meten gebruikten we de Timed Up and Go test (TUG), een gemakkelijke objectieve test die we uitvoerden bij de mensen thuis. Gezondsheidstatus meetten we met een artrose specifieke vragenlijst (Dutch AIMS SF); het omvat pijn, stijfheid, lichamelijke functioneren, sociaal functioneren en stemmingssymptomen. Patiënten in de interventiegroep verbeterden significant op de somscore van de Dutch AIMS SF. Er was geen verschil in verschuiving naar normale TUG tijden tussen de interventiegroep en de controlegroep. Huisartsen en fysiotherapeuten werden niet vaker bezocht in de interventiegroep. Er leek een trend te zijn richting meer medicatiegebruik in de interventiegroep, maar dit was niet significant.

Deze studie laat zien dat een interventie van beperkte intensiteit een trend naar beter functioneren bewerkstelligt. Het kan derhalve een aanvulling zijn op de huidige zorg voor oudere artrosepatiënten in de Nederlandse huisartsgeneeskundige zorg.

Hoofdstuk 10

In dit hoofdstuk worden de resultaten van de verschillende studies afgezet tegen de literatuur. De implicaties worden besproken, alsmede een aantal aanbevelingen. De bevindingen suggereren dat men er niet zomaar van uit kan gaan dat ouderen garant staan voor hun inbreng en betrokkenheid. Dit proefschrift laat zien dat hun inbreng een belangrijk iets is, maar dat het complex is. Het is een onderdeel van patiëntgerichte zorg en is een van de hoekstenen van huisartsgeneeskundige zorg. We moeten daarom de focus op inbreng en betrokkenheid niet verliezen. Ondanks dat we de juiste weg naar inbreng en betrokkenheid niet hebben gevonden, bleek dat huisartsen en ouderen vonden dat het van belang is.

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Curriculum vitae

Raymond Wetzels werd geboren op 20 juli 1973 te Nijmegen. Hij groeide op in Twente, het middelbaar onderwijs volgde hij op het Pius X College in Almelo. In 1991 keerde hij terug naar Nijmegen om de studie Geneeskunde te gaan volgen aan de toen nog Katholieke Universiteit Nijmegen. In 1998 behaalde hij zijn artsexamen. Gedurende zijn studententijd was hij actief als bestuurslid van de Medische Faculteits Vereniging Nijmegen (MFVN). In 1999 begon hij aan de huisartsenopleiding in Nijmegen. Grotendeels volgde hij de opleiding part-time, in januari 2004 rondde de huisartsenopleiding af. In september 2000 startte hij, eveneens part-time, met het in dit boek beschreven onderzoek bij de WOK. Naast dit onderzoek was hij gedurende deze jaren actief als bestuurslid van de Landelijke Organisatie van Aspirant Huisartsen (LOVAH). In januari 2005 is hij, als derde huisarts, toegetreden tot huisartsenmaatschap De Zuiling in Elst.